FAMILY NEEDS AND FAMILY QUALITY OF LIFE FOR TAIWANESE FAMILIES OF CHILDREN WITH INTELLECTUAL DISABILITY AND DEVELOPMENTAL DELAY

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ABSTRACT

This dissertation consists of four related chapters including an introductory overview of all four chapters, a report on family needs, a report on family quality of life, and a summary of implications for the conceptual framework. Chapter 1, the introductory overview, presents background information of Taiwan and describes the family quality of life conceptual framework as the context of the research. It further summarizes information in chapters 2 to 4. Using descriptive and ANOVA results from a survey study, Chapter 2 investigates family quality of life – the outcome in the conceptual framework. Chapter 3, on the other hand, addresses family needs – the input factor in the conceptual framework. Based on findings from the previous two chapters, Chapter 4 revisits the conceptual framework and discusses the relationship between family needs and outcomes.

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TABLE OF CONTENTS

LIST OF FIGURES viii

LIST OF TABLES ix

CHAPTER 1: Background, Conceptual Framework, and Scope of Dissertation Research 1

- Introduction 1
- Family Quality of Life Conceptual Framework 4
- Overview of Chapters 2 through 4 5
  - Outcome-Family Quality of Life 6
  - Input-Family Needs 6
- Implications for Theory Development and Future Research 7
- References 8

CHAPTER 2: Family Quality of Life for Taiwanese Families of Children with Intellectual Disability and Developmental Delay 11

- Abstract 11
- Introduction 12
  - Family Outcome Studies and Family Quality of Life Conceptual Framework 14
  - Family Quality of Life Research 16
- Methods 21
  - Participants 21
  - Measure 23
  - Data Analysis 25
- Results 26

Overall Family Quality of Life 26
Group Difference 27
Discussion 29
Limitations of Study 29
Summary of the Findings 30
Future Directions 33
Conclusion 36
References 37
CHAPTER 3: What Families Need: Validation of the Family Needs Assessment for Taiwanese Families of Children with Intellectual Disability and Developmental Delay 43
Abstract 43
Introduction 44
Family Needs Research 45
Gaps in Family Needs Research on Taiwanese Families 47
Methods 50
Scale Development Procedures 50
Participants 56
Measures 59
Data Analysis 61
Results 63
Psychometric analyses for the FNA 63
Family Needs Group Difference - Child Characteristics 70
Family Needs Group Difference - Family Characteristics 72
Discussion 74

Limitations 74

Analysis of Results and Family Literature 75

Future Direction for the FNA 77

Conclusion 79

References 81

CHAPTER 4: Revisiting the Conceptual Framework: Research Agenda 89

Abstract 89

Introduction 90

Possible Explanations of Non-correlation 90

Limited Support of the Hypothetical Relationship 91

Measurement Issues 92

Implications for Conceptual Framework and Future Research 93

Summary 96

References 97

Appendix A: Survey Protocol 98

Appendix B: Complete Factor Loading Table (Pattern Matrix) 114

LIST OF FIGURES

Figure 1. Chapter overview within the revised family quality of life conceptual framework. 5

Figure 2. The revised family quality of life conceptual framework (Chiu et al., 2013).............. 15

Figure 3. Translation and adaptation procedures for FNA.. 54

Figure 4. The proposed family quality of life conceptual framework... 94

LIST OF TABLES

Table 1 Demographics of Participants 22

Table 2 Family Quality of Life Subdoman Correlation Matrix 25

Table 3 Descriptive Statistics of Total and Subdoman Scores 27

Table 4 Analysis of Variance of Child Factors on Family Quality of Life 29

Table 5 Logical Domains of Family Needs 52

Table 6 Demographics of Participants 58

Table 7 Factor Correlation Matrix 64

Table 8 Item Loading on Factors 66

Table 9 FNA Domain Descriptive Information 69

Table 10 Descriptive Statistics of Child Factors 70

Table 11 Analysis of Variance of Child Factors on Family Needs 71

Table 12 Descriptive Statistics of Family Factors 72

Table 13 Analysis of Variance of FamilyFactors on Family Needs 73

CHAPTER 1: Background, Conceptual Framework, and Scope of Dissertation Research

Introduction

There is a fact that transcends social classes, cultural differences, and geographical boundaries: Families play important roles in children's lives. The variety of roles that parents of children with disabilities play, including primary caregivers, organization members, teachers, service developers, decision-makers and advocates, confirms the significance of their involvement (A. P. Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). Coinciding with the deinstitutionalization movement and increase of life expectancy, more and more family members are assuming crucial roles in ensuring a high quality of life for people with disabilities (H. R. Turnbull et al., 2007).

Research on families of individuals with disabilities increasingly is focusing on enhancing family outcomes (Cohen, Holloway, Dominguez-Pareto, & Kuppermann, 2013; Trivette, Dunst, & Hamby, 2010). Rather than identifying less advantaged family characteristics that may lead to negative family and child outcomes, researchers have begun to investigate what the positive outcomes are and how the child and family can benefit from environmental supports. (C. Chiu et al., 2013).

Family members, not only parents but also siblings and grandparents, sometimes receive and often provide support because their lives are interrelated with their family members with disabilities (Janicki, McCallion, Grant-Griffin, & Kolomer, 2000; Stoneman, 2005). The *Analysis of the Study on Needs of People with Disabilities* (Ministry of Interior, 2013) randomly sampled 19,301 people with disabilities and revealed that 92.8% of Taiwanese with disabilities live at home, where family members assume primary caregiver roles for more than half of them

(Department of Statistics at Ministry of Interior, 2012). The primary reason for people with disabilities living in an institution is that family members can no longer assume the caregiving role. Additionally, 23.6% of the sample reported that they have multiple family members with disabilities in the household.

The impressive number of individuals with disabilities supported by family members did not go unnoticed by researchers in disability-related fields. However, the majority of family studies have centered on individual outcomes, e.g., well-being of the primary caregivers or mothers (Chou, Chiao, & Fu, 2011; Lee et al., 2009; Lin et al., 2009). In contrast, there have not been as many studies on Taiwanese families that have aimed to describe and explore research questions at a family needs or outcomes level except for the works of Hsu (2007), Tang et al. (2005), and Wang (1993).

Similar to research, policy in Taiwan is beginning to reflect the trend of utilizing strategies to support families and aligning with the disability core concepts of Family Integrity and Family Centeredness (H. R. Turnbull, Beegle, & Stowe, 2001). The civil right movements and policy reform in the past two decades reveal the shift in societal perspectives over time and the enhancement of government support (League of Welfare of People with Disabilities, 2011). Article 51in People with Disabilities Rights Protection Act (2011) and the Regulations of Services for Family Caregivers of Individuals with Disabilities (2012) mandate local government to provide and supervise services developed for and delivered to family caregivers (biological and legal) related to individuals with disabilities. The services include: home-based services, community-based services, center-based services, respite care services (short-term and long-term), training and support, and emotional support. Furthermore, Article 31 in the Protection of

Children and Youths Welfare and Rights Act (2012) further requires early intervention, medical services, educational services, and family support for families of children with developmental delay under six.

Nationally, Taiwan government subsidies for disability welfare exceeded 43 million U.S. dollars. While National Health Insurance is mandatory for all citizens, mid-to-low-income families (i.e., families having average per capita income less than 2.5 times the minimum living expenses standard for the administrative division of residency) qualify for subsidies for National Health Insurance (Ministry of Foreign Affairs, 2011). Low-income families of children with disabilities are eligible for a 151 U.S. dollars subsidy per child per month. Additionally, children with disabilities can receive aid for early intervention and education.

Governmental family support resource distribution, however, is unequal among the administrative divisions (i.e., cities and counties) according to the inventory of resources for people with disabilities which was prepared by a Ministry of Interior commission project with funding from the National Science Council (M. Chiu, Han, Hong, Bei, & Zhang, 2010). With the average monthly expense for families of individuals with disabilities being approximately 1,000 U.S. dollars, over half of the families indicated insufficient income to balance their household expenses (Ministry of Interior, 2013). While national and local government agencies strive to provide support to individuals with disabilities and their families, there are still unidentified needs and outcomes among this population.

In sum, further research in family outcomes and family needs is warranted to ensure adequacy and effectiveness of services and supports in Taiwan. The purpose of the dissertation, therefore, is to explore family outcomes and needs in Taiwanese families of children with intellectual disabilities and developmental delays from a family quality of life theory perspective. I introduce the conceptual framework and connect each chapter to this framework in the subsequent sections.

Family Quality of Life Conceptual Framework

Despite that researchers have developed and validated measures to obtain information related to family quality of life, the absence of conceptual frameworks, theories, and agreed-upon definitions remained problematic to family outcome studies until Zuna, Summers, Turnbull, Hu, and Xu (2010) synthesized previous research to propose a definition of family quality of life and a foundational conceptual framework. Zuna et al. (2010) defined family quality of life as “ 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 (p.262).”

Moreover, Zuna et al. (2010) used existing theory, literature, and researcher assumptions to identify a series of factors and to propose an initial conceptual framework of family quality of life. Over the past few years, the field has developed a more comprehensive understanding of the factors. C. Chiu and colleagues (2013) reviewed more recent studies and have proposed a new iteration of the conceptual framework (Figure 1), which includes the input (i.e., family needs and strengths), systemic factors (i.e., the macro-environment, including societal values, policies, systems, and programs), the family-unit factors (i.e., family characteristics, family dynamics), the individual-member factors (i.e., demographics, characteristics, and beliefs), individual and family support factors (i.e., resources and strategies that aim to promote outcomes), and outcome (i.e., family quality of life). For space conservation, I address the family quality of life conceptual framework with more details in Chapter 2.

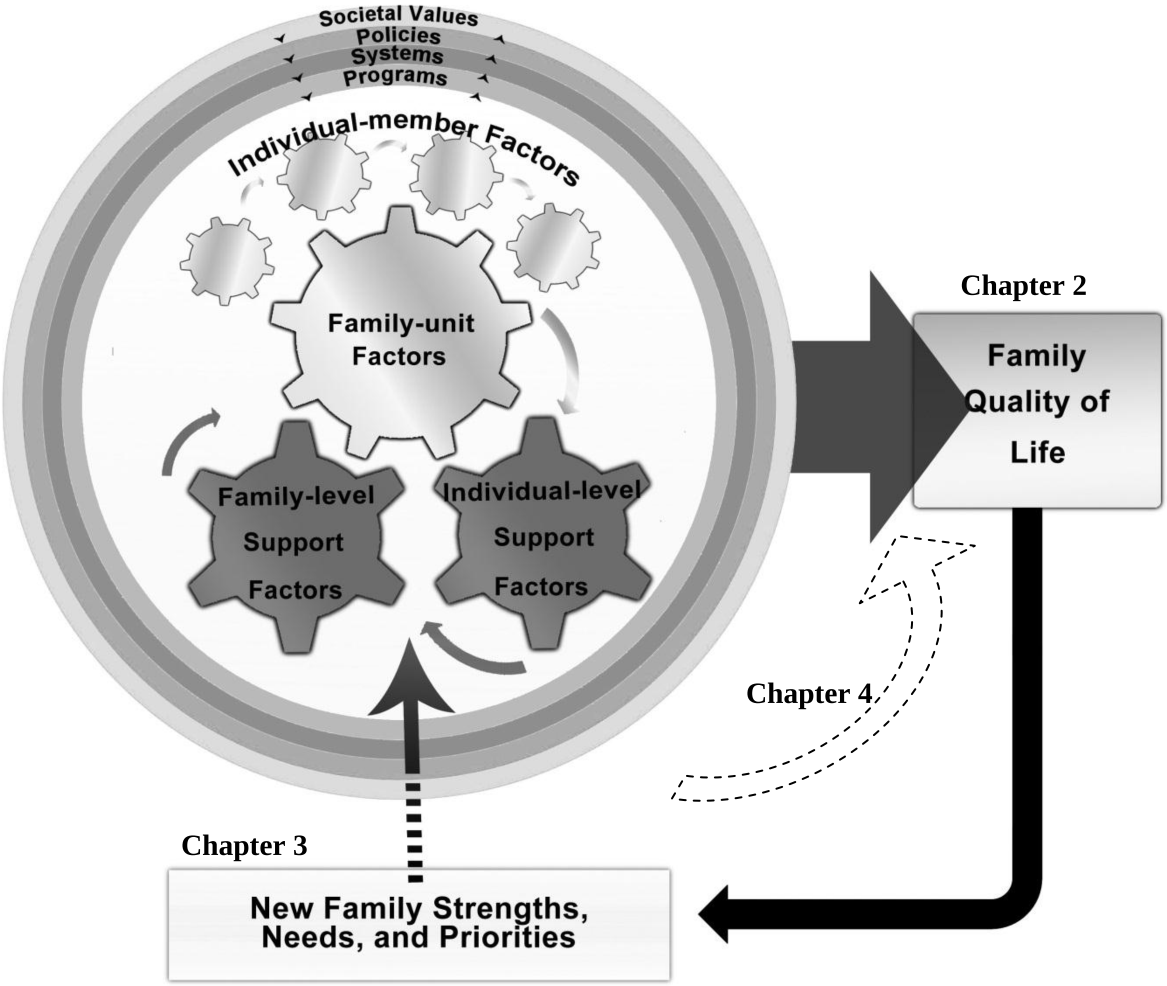

Figure 1. Chapter overview within the revised family quality of life conceptual framework (C. Chiu et al., 2013).

Overview of Chapters 2 through 4

Chapters 2 and 3 highlight two major components, family quality of life outcomes and family needs, in the family quality of life conceptual framework. Chapter 4 provides a discussion on correlation between those two constructs.

Outcome-Family Quality of Life

In Chapter 2, I address the construct of family quality of life which has been the focus of more research than other framework constructs. This chapter connects findings from a study on 333 Taiwanese families of children with intellectual disability and developmental delay to the family quality of life conceptual framework. Based on the results of the 21-item Beach Center Family Quality of Life Scale, Taiwanese families reported relatively higher family quality of life in Family Interaction and Physical/Material Well-being, and relatively lower family quality of life in Parenting and Emotional Well-being. Further, the family quality of life rating varies with different household income and the interaction between severity of disability and additional support at home.

Input-Family Needs

After analyzing the family quality of life outcomes, I shift attention in Chapter 3 to family needs, a construct with substantially less research. Chapter 3 thoroughly documents the validation process of the Family Needs Assessment (FNA), a 7-factor 73-item measure. It includes procedures in scale development, translation, survey distribution, content of the survey package, data analyses, results, discussion, and conclusion. The exploratory factor analysis results propose an underlying factor structure of the FNA and provide a foundation for understanding family needs in Taiwan. This sample of 401 families of children with intellectual disability and developmental delay reported highest needs in Hope and Disability-related Services. In addition, the level of family needs varies across groups with different child and family characteristics.

Implications for Theory Development and Future Research

Finally, in chapter 4, I revisit the family quality of life conceptual framework. There was a lack of evidence in the hypothetical negative correlations between family needs and family quality of life in the dissertation. I present potential reasons that the findings did not align with the conceptual framework and discuss implications of such findings in theory development/future research.

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CHAPTER 2: Family Quality of Life for Taiwanese Families of Children with Intellectual Disability and Developmental Delay

Abstract

The family quality of life conceptual framework has implications for researchers, practitioners, and policy makers in understanding family outcomes within the context of systemic, family-unit, individual member-unit, and support factors (Chiu et al., 2013; Zuna, Summers, Turnbull, Hu, & Xu, 2010). This study uses the Beach Center Quality of Life Scale to document current conditions for Taiwanese families of children with intellectual disability and developmental delay and to connect findings with the conceptual framework. The author explores and discusses Taiwanese families' ratings of satisfaction in the sequence from high to low: Family Interaction, Physical/Material Well-being, Parenting, and Emotional Well-being. Further, the author investigates differences among groups with various characteristics and found the family quality of life rating varies with different household income and the interaction between severity of disability and additional support at home. In sum, the study represents an initial effort in understanding family quality of life of Taiwanese families of individuals with disabilities and suggests using family quality of life as an indicator of positive outcomes in research, policy, and practice.

Chapter 2

Family Quality of Life for Taiwanese Families of Children with Intellectual Disability and Developmental Delay

Introduction

Historically, the majority of disability research in Taiwan has centered on outcomes for individuals with disabilities and generally overlooked the well-being of families of individuals with disabilities (Chou, Lin, Chang, & Schalock, 2007; Hsu, 2007). In the past decade, there has been an increase in recognition of the significance of supporting families as a way to improve outcomes for individuals with disabilities (A. P. Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). The rise in awareness has not only impacted policy-making in Taiwan but also prompted professionals to investigate outcomes for the family caregivers and the family unit (Chou, Lee, Lin, Kröger, & Chang, 2009).

Family studies are especially important in the context of the traditional values in Taiwan. Similar to other Asian countries, family members in Taiwan consider themselves responsible to take care of each other (Chan & Lee, 2004). While 92.8% of individuals with disabilities live at home, family members assume primary caregiver roles for more than half of them (Department of Statistics at Ministry of Interior, 2012). Among the 1,100,436 individuals with disabilities, 10% are children below the age of 18 (*n*=113,599) who mostly live in a nuclear household (parents and children; 37.79%) or a three-generation household (grandparents, parents, and children; 31.15%). Because of traditional values rooted in filial piety, over half of the elders co-reside with and are taken care off by their married sons and daughters-in law (Ku, Liu, & Wen, 2013). Having a child with disabilities in the family certainly increases the demand of caregiving responsibilities. While the elders co-residing in the household may become a source of stress, they could also be a reliable additional source of support to the caregiver (Chou et al., 2009).

In 2012, the Ministry of Interior issued the Regulations of Services for Family Caregivers of Individuals with Disabilities as a by-law of the People with Disabilities Rights Protection Act (2011). Article 3 in the regulation holds local government agencies accountable for delivering services for family caregivers (i.e., caregivers who co-reside with and are related either by reason of biology or marriage to individuals with disabilities). It further requires local government agencies to evaluate and provide technical assistance periodically to organizations responsible for service delivery. The regulation provides detailed guidelines for service delivery (i.e., eligibility determination, nature of services, funding sources, personnel qualification, and environment specification). It mandates individualized and appropriate services for family caregivers to decrease their caregiving burden, with the intent being to improve the caregivers' quality of life.

Despite the fact that the policy provides guidelines for service delivery, there are no research findings or other reports documenting the regulation's implementation and outcomes. Presumably, the long-term impact of individualized and appropriate family services in Taiwan is enhanced family outcomes (R. I. Brown, Hong, Shearer, Wang, & Wang, 2010). However, with the scant research on family outcomes in Taiwan, the current status related to families, caregivers, implementations, and outcomes remains unclear. Accordingly, it will be useful to identify a systematic method for evaluating the nature and effect of ongoing supports and services for families at a family-unit level.

This research aims to report family quality of life outcomes related to Taiwanese families of children with intellectual disability and developmental delay. Furthermore, this study explores impact of family, individual, and support factors on family quality of life outcomes in Taiwan. In the following sections, I describe family outcome studies and the family quality of life conceptual framework. Then, I summarize relevant research on family quality of life.

Family Outcome Studies and Family Quality of Life Conceptual Framework

A. P. Turnbull, Summers, Lee, and Kyzar (2007) selected and reviewed 28 relevant research articles to investigate the past and current emphasis on family outcomes. In exploring the current conceptualizations and measurement of family outcomes related to families of individuals with disabilities, the authors found studies on family well-being, adaptation, and family function (n=20) less likely to be grounded in conceptual frameworks and focused on new instrument development as compared to family quality of life studies (n=8). The first group of studies (i.e., studies on family well-being, adaptation, and family function) usually operationalized family outcomes as subjective feelings about mental health, stress, caregiving burden, parenting efficacy, marital relationship, and family relationships. While covering similar dimensions, family quality of life studies also connect the outcomes to a theoretical basis.

The construct of family quality of life provides an important ecological framework for family outcomes evaluation. 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 et al., 2010, p. 262).” Zuna et al. (2010) conducted a comprehensive literature synthesis and proposed an overarching conceptual theory as a foundation to build a family quality of life theory. Figure 2 depicts an updated conceptual framework derived from a more recent literature review (Chiu et al., 2013). Family strengths, needs, and priorities provide input for systemic factors, family-unit and individual member factors, and support factors. The multiple factors interact with each other and produce the family quality of life outcome. Finally, the family quality of life outcome contributes to new family strengths, needs, and priorities.

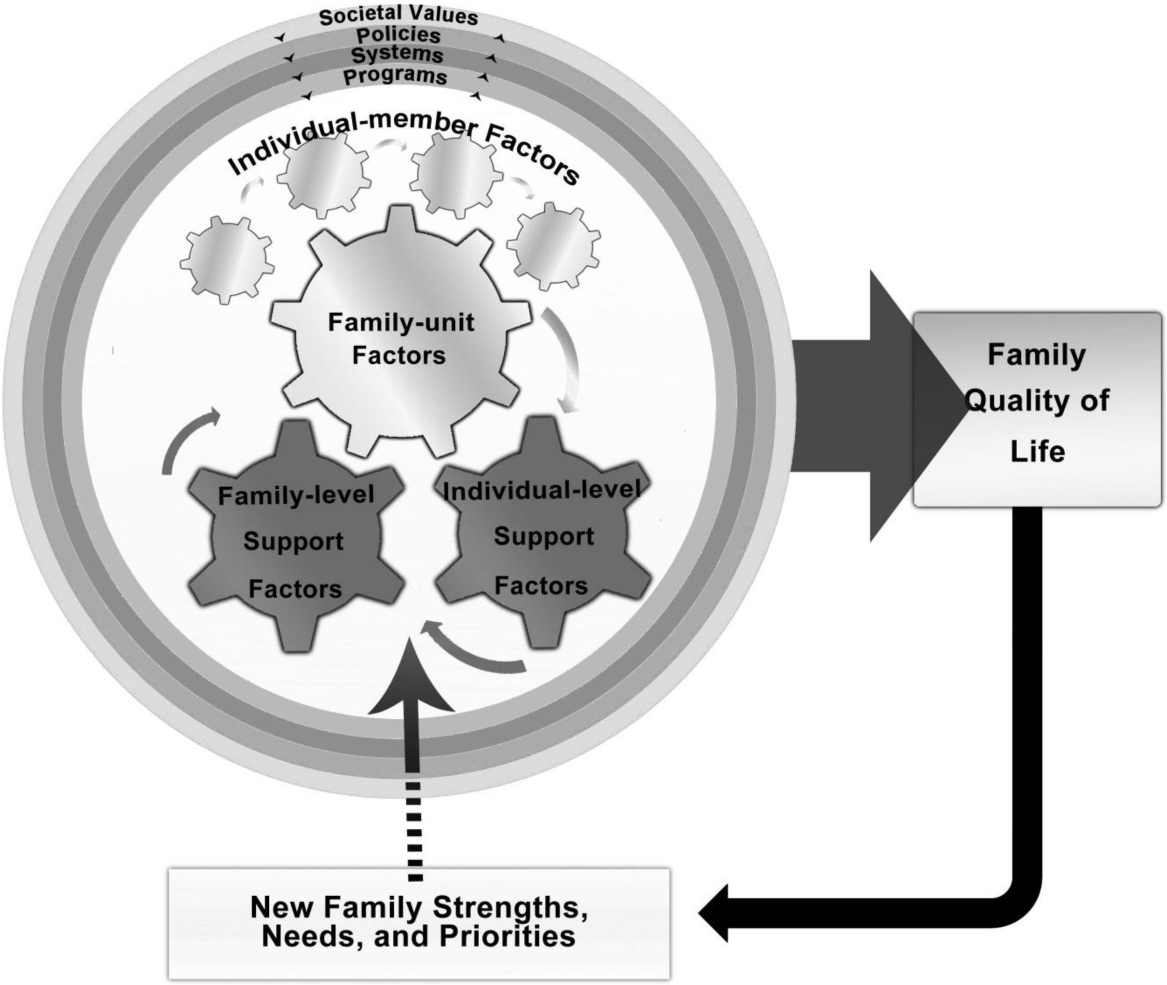

Figure 2. The revised family quality of life conceptual framework (Chiu et al., 2013).

In the past decades, researchers have developed measures with reliability and validity to collect data on family quality of life. Hu, Summers, Turnbull, and Zuna (2011) reviewed 16 existing measures published between 1980 and 2009. Two of the family quality of life measures identified by the authors were validated and used in disability studies on more than one ethnic groups. The two tools, the Family Quality of Life Survey-2006 (I. Brown et al., 2006) and the Beach Center Family Quality of Life Scale (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006), both covered domains related to Family Interaction, Emotional Well-being, Physical/Material Well-being, and Disability-related Services. In addition to the overlapping domains, the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) had one domain in Parenting; whereas the Family Quality of Life Survey-2006 (I. Brown et al., 2006) contained additional domains in Support from Other People, Influence of Values, Careers and Planning for Careers, Leisure and Recreation, and Community Interaction.

It is problematic that both measures contain non-outcome items (e.g., family supports). In theory, family quality of life has been conceptualized as an outcome. Both aforementioned tools contain items related to services and supports, which theoretically are influential factors of family quality of life outcomes. Given that the outcome measure includes items such as “My family member with special needs has support to make progress at school or workplace,” it became difficult to interpret findings from a theoretical basis. Nevertheless, the past literature provides foundations to understand how families perceive their family quality of life.

Family Quality of Life Research

As family quality of life research evolved, there has been an increase in family quality of life studies in non-Western countries (Wang, 2010). Unfortunately, the majority of family research in Taiwan has reported family caregivers' individual quality of life, where the caregivers primarily are mothers; only a few studies examined family quality of life at a family-unit level (Hsu, 2007; Tang et al., 2005). To expand understanding of family studies for a Taiwanese population, I have included in the review in this section international family quality of life studies and Taiwanese family caregivers' quality of life studies.

Family quality of life outcomes in Taiwan. In a cross-cultural comparative study, R. I. Brown et al. (2010) examined responses on the Family Quality of Life Survey- 2006 (I. Brown et al., 2006) from 83 Taiwanese families of children with autism (aged 1-14) in one urban area. The results showed Family Relationships as the area with highest satisfaction. On the contrary, the two areas with lowest satisfaction were Disability-Related Service and Community Involvement. When compared to other countries (i.e., Canada and Australia), Taiwan's overall family quality of life satisfaction results were relatively low. R. I. Brown et al. (2010) argued that the results might be associated with society's negative perspectives toward disability and the lack of appropriate social services in Taiwan. This conclusion, based upon a small and specific sample (urban families of children with autism), might not reflect family quality of life and potential group differences among Taiwanese families of children with other disabilities.

A literature search via Google Scholar revealed that there have been only two studies published in Taiwan using the term "family quality of life" and attempting to investigate quality of life at a family-unit level with items related to all family members. Both were scale validation studies. Tang et al. (2005) developed and validated a 35-item 6-factor family quality of life measure on 152 Taiwanese families but did not report descriptive results in the study. In order to validate a family quality of life measure, Hsu (2007) collected responses from 397 families of young children with disabilities (aged 0-7). The author proposed a 3-factor 17-item scale and reported the overall and factor descriptive results. On a 4-point scale (1-*strongly disagree* to 4-*strongly agree*), respondents in the study generally indicated agreement with the statement that they were satisfied with the overall family quality of life (*M*=2.79, *SD*= .39). Among the three factors, respondents reported highest level of satisfaction in the areas of Family Interaction and Emotional Well-being (*M*=2.89, *SD*= .43), followed by Family Environment and Community (*M*=2.77, *SD*= .39), and finally Family Productivity (*M*=2.62, *SD*= .47). However, the results from both studies need to be interpreted with caution, given that both contained methodological concerns (e.g., inadequate sample size, inadequate number of items for one factor). Finally, neither measure has yet to be employed in further studies.

Factors influencing family quality of life and caregivers' quality of life. Using the family quality of life conceptual framework as guidance, I organized research findings according to three categories: (a) family-unit factors, (b) individual-member factors, and (c) support factors.

First, family-unit factors (i.e., family characteristics, family dynamics) can affect the members' perceptions toward family and individual quality of life. Findings from past studies confirmed that family income is a significant determinant of individual and family quality of life in both the U.S. and Taiwan (Hsu, 2007; Hu, Wang, & Fei, 2012; Lin et al., 2009; Park, Turnbull, & Turnbull, 2002; Wang et al., 2004). Families with higher family income reported statistically significantly higher family quality of life and caregivers' individual quality of life, particularly in Emotional and Physical/Material Well-being. In contrast, poverty has negative impacts towards family quality of life. Another family-unit factor that had been identified in research is religious belief. Poston and Turnbull (2004) found that families reported that their spiritual beliefs (faith that a higher being would take care of them) positively affected family quality of life.

Second, individual-member factors (i.e., demographic traits, characteristics, and beliefs of a family member) interact with family-unit factors and affect family outcomes. Caregivers of individuals with less severe disabilities reported higher individual and family quality of life as compared to caregivers of adults with more severe disabilities (Chou, Chiao, & Fu, 2011; Walton-Moss, Gerson, & Rose, 2005; Wang et al., 2004). Additionally, type of disability, occurrence of behavior problems, and residential arrangement of the individuals with disabilities may also affect family quality of life (R. I. Brown, Geider, Primrose, & Jokinen, 2011; Jackson, Wegner, & Turnbull, 2010; Werner et al., 2009).

Third, supports available to families and individual family members impact family quality of life regardless of the sources (i.e., formal services or informal) or typologies (e.g., emotional, physical, material/instrumental, or informational). In a comprehensive research synthesis, Kyzar, Turnbull, and Summers (2012) found that family support significantly related to family outcomes. However, the inconsistency in definition of supports and in determining support factors as either influential factors or outcomes led to fewer studies examining the relationship between supports and family quality of life. In one survey study, families and service providers indicated family quality of life as an important outcome of services (Dunst & Bruder, 2002). The other literature promoting family quality of life as an outcome of supports have been conceptual papers (Kober & Eggleton, 2009; Summers et al., 2005). At an individual level, availability of a substitute person to care for individuals with disabilities has been significantly associated with caregivers' quality of life (Chou, Pu, Kroger, & Fu, 2010).

To sum up, there is a lack of understanding of Taiwan's family quality of life in both the perspectives of the nation as a whole and among groups within the nation. Using findings from the international family quality of life studies and Taiwan caregiver quality of life studies as basis, I have identified key research questions and formed probable hypotheses. This study aims to explore family quality of life in Taiwan and identify whether the family-unit and individual member-unit factors identified in past studies in other countries are significantly associated with Taiwanese family quality of life. This study answers the following research questions:

1. What are the family quality of life outcomes of Taiwanese families of children with disabilities?
2. Are there significant differences in responses to the FQOL scale among groups with different household income, severity of child's disability, additional support at home in Taiwan?
    a. Is there an interaction of household income, severity of child's disability, additional support at home in regard to family quality of life?
    b. Is there an interaction of household income and severity of child's disability in regard to family quality of life?
    c. Is there an interaction of severity of child's disability and additional support at home in regard to family quality of life?
    d. Is there an interaction of household income and additional support at home in regard to family quality of life?

e. Is there a difference among groups with different household income in regard to family quality of life?
f. Is there a difference between the levels of the severity of child's disability in regard to family quality of life?
g. Is there a difference between the groups with and without additional support at home in regard to family quality of life?

Methods

In the following sections, I introduce participant characteristics, measures, and data analysis plan. I started data collection upon approval from the University of Kansas Human Subjects Committee.

Participants

I mailed 500 survey packets through Chunghwa Postal Service (equivalent to U. S. Postal Service) to service providers (e.g., social workers, teachers). These service providers from eight local early intervention centers, five parent support groups, and 11 schools distributed the survey packets to family respondents. Within four weeks of distribution, I received 409 completed surveys (81.8% return rate). After data screening (i.e., examining distribution of items, identifying outliers, identifying missing values), the sample was reduced by 76 respondents to 333. The 76 respondents who were eliminated did not provide information as to one or more of the independent variables (demographic questions) or did not respond to 15% or more items of the family quality of life section (missed more than three questions). Most of the 333 respondents were parents of the child with disabilities (*n*=306, 91.9%), female (*n* =266, 79.9%), non-aboriginal Taiwanese (*n*=307, 92.2%), married or living with a partner (*n*=271, 81.4%) and graduated from high school (*n* =276, 85.8%). Table 1 provides detailed information on demographics of the respondents.

Table 1

Demographics (N=333)

	n	Percentage
Gender of the respondent		
Female	266	79.9
Male	67	20.1
Relationship to the child with disability (*n*=332)		
Parent	306	91.9
Grandparent	10	2.4
Sibling	8	2.4
Other relatives nor non-relatives	6	1.8
Nationality (*n* =332)		
Taiwanese, non-aboriginal	307	92.2
Taiwanese, aboriginal	14	4.2
Chinese and other	11	3.3
Age group (*n* =322)		
Below 35	61	18.3
36-50	220	66.1
Above 51	41	12.7
Marital status (*n* =330)		
Married/ living with a partner	271	81.4
Divorced or separated	38	11.4
Never married	18	5.4
Widowed	3	.9
Employment status (*n* =329)		
Working full-time for pay or profit for a company or family business	143	42.9
Working part-time for pay or profit for a company or family business	33	9.9
Unemployed but looking for work	17	5.1
Not employed (e.g., stay-at-home, retired, public assistance pay)	135	40.5
Educational level		
Elementary and middle school	47	14.1
High school and tech school	177	56.1
College and above	99	29.7

Administrative district type		
Urban	141	42.3
Suburban	132	39.6
Rural	60	18.0
Geographical location		
Northern Taiwan	127	38.1
Southern Taiwan	122	36.6
Mid-Taiwan	44	13.2
Eastern Taiwan	40	12.0
Monthly household income		
Below 29,999 NTD	80	24.0
30,000~69,999 NTD	176	52.9
Above 70,000 NTD	31	23.1
Additional Support		
No	210	63.1
Extended family members (e.g., grandparents) or hired workers	123	36.9
Child’s gender		
Female	116	34.8
Male	217	65.2
Child’s age		
Younger child (0-6)	129	38.7
School age (7-18)	184	61.3
Severity of child’s disability		
Developmental delay	64	19.2
Mild intellectual disability	98	29.4
Moderate intellectual disability	95	28.5
Severe and profound intellectual disability	76	22.8

Note. Because of missing data, the percentages of some variables do not add up to 100%.

Measure

Each participant received a stamped self-addressed envelope to use in returning the survey packet and an incentive of a gift card for 100 N.T. dollars (approximately three U.S. dollars). The survey packet contained 21 items of the Beach Center Family Quality of Life Scale (hereafter referred as the Beach Center Scale) and demographic questions.

Beach Center Scale. The Beach Center Scale (Hoffman et al., 2006) measures families’ perceived satisfaction in five domains of life: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-related Services. The Beach Center Scale has a satisfactory internal consistency (α=.88) and test-retest reliability (.60 to .77). For convergent validity, the Family Interaction domain has an acceptable correlation with the Family APGAR (r (87) = .68, $p < .001$); whereas the Physical/Material Well-being domain has an acceptable correlation with the Family Resource Scale ($r = .60$, $p < .001$) (Hoffman et al., 2006; Summers et al., 2005).

Since the purpose of collecting data with the Beach Center Scale in the study was to examine family outcomes, I removed the four Disability-related Services items and included 21 outcome-related items across four domains in this study. Although the 21-item version has not been used in studies on families of individuals with disabilities, Zuna, Selig, Summers, and Turnbull (2009) found the four-factor structure plausible for 566 parents of kindergartners without disability in the U.S.

Taiwanese families responded to items on a 5-point Likert-type scale to indicate their level of satisfaction on the items (1- *very dissatisfied* to 5-*very satisfied*). Refer to Hoffman et al. (2006) for a complete description of all 21 items. Results from the confirmatory factor analysis on this Taiwanese sample indicated adequate fit of the sample data to the four-factor structure (χ^2 (179) = 663.41, $p < .001$, CFI = .98, RMSEA = .085).

Demographic questions. The survey included polychromous questions on information of the respondents (i.e., gender, relationship to the child, nationality, date of birth, marital status, employment status, educational level, geographical location, household income, additional support at home) and their children with disabilities (i.e., gender, data of birth, severity of disability).

Data Analysis

As mentioned in the section on participants, I conducted data screening before the analyses. To answer the first research question, I reported descriptive results to describe the overall family quality of life of Taiwanese families with the total mean score and domain mean scores. Next, because the four domains in Beach Center Scale were highly correlated (as shown in Table 2), I chose to compute the total mean score of the Beach Center Scale as the dependent variable for the factorial analysis of variance (ANOVA) in answering the second research question.

Table 2

FQoL Subdomain Correlation Matrix

	Family Interaction	Parenting	Emotional Well-being	Physical/Material Well-being
Family Interaction	1	$.865^{**}$	$.834^{**}$	$.714^{**}$
Parenting		1	$.803^{**}$	$.711^{**}$
Emotional Well-being			1	$.696^{**}$
Physical/Material Well-being				1

Note. ** $p < .01$

The 3-way (3 × 2 × 3) ANOVA examined the interaction effects and main effects of household income, severity of child’s disability, and additional support at home on family quality of life. The household income variable consisted of three levels (1-lower income families; 2- medium income families; 3- higher income families). The disability severity variable consisted of three levels (1- mild intellectual disability and developmental delay; 2-moderate intellectual disability; and 3- severe and profound intellectual disability). Finally, the variable of additional support at home consisted of two levels (1-no additional support at home; 2-additional support at home). Fisher's Least Significant Difference (LSD) *post hoc* tests were performed to identify significant mean differences between individual groups of children. The level of statistical significance was set at $p < .05$ for all tests (Tabachnick & Fidell, 2007). I examined the result of the Levene' test of equality of error variance matrix to ensure the fundamental assumptions of homogeneity of variances were not violated (Keppel & Wickens, 2004).

Results

Overall Family Quality of Life

With more than half of the families classified as medium-income families, having a child with mild intellectual disability, and having no additional support at home, the total mean score on the 21-item Beach Center Scale indicated satisfaction in family quality of life (*M*= 3.48, *SD*= .75). The domain with highest satisfaction was Family Interaction (*M*= 3.57, *SD*= .63), followed by Physical/Material Well-being (*M*= 3.52, *SD*= .64) and Parenting (*M*= 3.42, *SD*= .67). Finally, families reported less satisfaction with Emotional Well-being (*M*= 3.37, *SD*= .72). Table 3 reports descriptive results of groups with different household income, severity of child's disability, and additional support at home. Consistently across groups, Taiwanese families reported relatively higher levels of satisfaction in Family Interaction and Physical/Material Well-being and relatively lower levels of satisfaction in Parenting and Emotional Well-being.

Table 3

Descriptive Statistics (N=333)

	Total Score *M(SD)*	Family Interaction *M(SD)*	Parenting *M(SD)*	Emotional Well-being *M(SD)*	Physical/ Material Well-being *M(SD)*
Household Income					
Lower income (*n*=80)	3.29(.68)	3.36(.80)	3.29(.71)	3.20(.76)	3.28(.66)
Medium income (*n*=176)	3.48(.60)	3.59(.69)	3.42(.65)	3.38(.68)	3.50(.61)
Higher income (*n*=31)	3.67(.62)	3.76(.76)	3.57(.66)	3.55(.69)	3.78(.59)
Severity of Disability					
Mild (*n*=152)	3.44(.68)	3.50(.78)	3.40(.72)	3.33(.74)	3.50(.65)
Moderate (*n*=95)	3.54(.56)	3.68(.64)	3.47(.61)	3.45(.69)	3.53(.60)
Severe (*n*=76)	3.48(.64)	3.58(.77)	3.41(.66)	3.37(.69)	3.53(.68)
Additional support at home					
No (*n*=201)	3.43(.64)	3.53(.74)	3.40(.68)	3.30(.72)	3.46(.67)
Yes (*n*=123)	3.56(.63)	3.64(.75)	3.47(.67)	3.50(.70)	3.62(.57)

Group Difference

Results from the Levene's test of equality of error were not significant at $p<.001$, showing that homogeneity of variance across groups was equivalent. The analyses found no significant interaction effect among household income, severity of disability and additional support at home. There was a significant interaction effect between severity of disability and additional support at home on the family quality of life total mean score in the sample, $F(2, 315) = 3.53$, $p = .03$, partial $\eta^2 = .02$. The interaction effect was explored further using the LSD *post hoc* test. Due to the high power and low variability, I decided to evaluate of the simple main effect of additional support within three levels of disability severity. The findings indicated that among families of children with mild intellectual disability and developmental delays, those with no additional support reported statistically significant lower satisfaction than those with additional support at home (3.42± .80 vs. 3.64± .74, $p = .01$). However, the differences in family quality of life were not statistically significant within families of children with moderate (3.60± .67 vs. 3.84± .56, $p > .05$) or severe/profound disabilities (3.69± .69 vs. 3.40± .89, $p > .05$).

There was a significant difference by household income in the family quality of life total mean score ($F(2, 315) = 5.376$, $p = .005$). However, the strength of the relationship with household income and family quality of life was weak with a small effect size (partial $\eta^2 = .03$). Follow-up LSD tests showed that families with lower household income reported statistically significant lower family quality of life (3.29± .68) as compared to families with higher household income (3.67± .62). Nevertheless, the follow-up tests revealed significant differences between neither families with lower and medium income nor families with medium and higher household income. The results are summarized in Table 4.

Table 4

Analysis of Variance of Child Factors on Family Quality of Life (N=333)

Source of Variance	SS	df	MS	F
Household income	4.155	2	2.077	5.376**
Severity of disability	.796	2	.398	1.031
Additional support at home	.221	1	.221	.572
Household income x Severity of disability	.157	4	.039	.101
Severity of disability x Additional support at home	2.725	2	1.363	3.526*
Household income x Additional support at home	.095	2	.048	.123
Household income x Severity of disability x Additional support at home	2.612	4	.653	1.690
Error	121.717	315	.386	

Note. * $p < .05$, ** $p < .01$

Discussion

I proposed research questions to explore family quality of life among Taiwanese families and to examine the associations between three factors (i.e., household income, severity of disability, and availability of additional support at home) related to family quality of life. In this section, I address the limitations of the study; summarize the findings; and propose future directions for research, policy, and practice.

Limitations of Study

Several limitations should be considered in deriving conclusions from the results. First of all, the majority of the respondents were families of children with intellectual disability and developmental delay. The sample limited generalization of the findings to families of individuals with other disabilities. Second, similar to the majority of family studies in the disability-related field, respondents in the study were primarily mothers (A. P. Turnbull et al., 2007). The responses from one family member might not be representative for all other family members. Future researchers should obtain responses from multiple members to the maximum extent culturally appropriate. Finally, the sample size in each sub-group was unequal. However, the results from the Levene's test for homogeneity of variance showed that each group of the independent variable has the same variance (Keppel & Wickens, 2004).

Summary of the Findings

Results from descriptive analyses indicated Taiwanese families expressed higher satisfaction in Family Interaction and Physical/Material Well-being as compared to Parenting and Emotional Well-being. Findings from the ANOVA supported the existence of the household income main effect and an interaction effect of severity of disability and additional support at home. In the subsequent sections, I connect findings with the family quality of life conceptual framework.

Overall family quality of life. In general, the findings showed relatively higher satisfaction in Family Interaction and Physical/Material Well-being as compared to Parenting and Emotional Well-being. I discuss each domain in the Beach Center Scale and align the findings with systemic factors from the family quality of life conceptual framework. These systemic factors are depicted as the outer circles in Figure 2.

Overall, Taiwanese families reported lower family quality of life domain mean scores as compared to the previous family quality of life studies in the U.S. that used the same measure (Beach Center Scale). Taiwanese families had 3.57 for the domain with the highest mean score (Family Interaction), while their counterparts in the U.S. had 4 or higher domain mean scores in Family Interaction, Physical/Material Well-being, and Parenting. It is worth noting that Turkish parents also had all domain mean scores under 4 (Bekir, 2011).This between-country difference supports the finding in the R. I. Brown et al. (2010) study that Taiwanese families had relatively lower satisfaction in family quality of life when compared to Western countries. Nevertheless, further investigation is needed to explore the reason behind the differences, controlling for other demographic variables.

Similar to previous studies (R. I. Brown et al., 2010; Hsu, 2007), this study identified Family Interaction relatively higher in regard to family quality of life. The traditional value of filial piety, derived from Confucianism, shapes the beliefs of Taiwanese families to promote family unity and harmony (Chan & Lee, 2004). The *societal value,* family-centered orientation in society, may explain the high levels of satisfaction in Family Interaction, given that the domain includes enjoying the presence of, showing affection to, and supporting each family member.

In contrast, the *systems* and *policies* factors may contextualize the high satisfactions in Physical/Material Well-being in Taiwanese families as the Beach Center Scale covered items related to medical care, transportation, safety, and financial expenses. Financially, the People with Disabilities Rights Protection Act (2011) mandates a government subsidy for education, medical, and transportation expenses for individuals with disabilities (Act 22, 23, 26, 27, 29, 58). Local education agencies are required to provide transportation between home and school for students who are not able to attend school with regular transportation (Act 27). Although it was controversial for unconstitutionally restricting individual liberty, the National Health Insurance (NHI) program launched in March 1995 has secured comprehensive health services for all citizens (Wu, 2013).

Further, *societal values* such as traditional child-rearing beliefs and over-emphasis on academic achievement may lead to lower satisfaction in Parenting (i.e., helping and teaching children to develop). In Asian society, there is a hierarchical relationship in families that children should always obey and honor parents and grandparents (Chan & Lee, 2004). It may be more difficult to accept children’s problem behaviors even if the behaviors are a manifestation of their disability. Additionally, the high regard toward academic achievement may result in lower satisfaction in parenting of children with disabilities who have not been successful in obtaining good testing scores at school (Groce & Zola, 1993).

The pressure from parenting under specific *societal values*, in turn, may affect Emotional Well-being (i.e., having support from people outside of the family and being able to address personal needs). In Asian countries, where one's loyalty is usually first and foremost to the family, parents are prepared to sacrifice personal needs for their children (Chan & Lee, 2004; Lee & Sun, 1995). Additionally, the traditional belief in Asian society considers disability as a punishment for sins committed by the parents themselves or their ancestors (Groce & Zola, 1993; Saetermoe, Scattone, & Kim, 2001). The sense of accountability for children’s behavior and achievement, in combination with the attempt to save face from stigmatization, prevent them from seeking assistance outside of the family (Chou et al., 2009).

Group difference. In this study, I explored impact of the influential factors (illustrated as cogs in Figure 2) on family quality of life. In theory, it is expected that the family-unit, individual-member, and support factors interact with each other in influencing family quality of life. Although I failed to find some interaction and main effects among selected variables (i.e., household income, severity of disability, and availability of additional support at home), it might not mean that the effects did not exist. The absence of statistically significant results and results with larger effect size could be due to the limited sample. More studies are warranted to explore how the three selected influential factors impact family quality of life.

Nevertheless, the findings documented that families with higher household income reported higher family quality of life. The results were consistent with those of Wang et al. (2004), Hu et al. (2012), Hsu (2007), and Park et al. (2002) regarding family income.

Contrary to past studies (Chou et al., 2011; Wang et al., 2004), I found no statistically significant differences across families of children with different levels of severity of disability. Furthermore, I found no differences between families with and without additional support at home. Nevertheless, when families of children with mild intellectual disability or developmental delay obtained additional support at home, they were more likely to have higher family quality of life. One possibility was that the families responded with dichotomized options (Yes/No) without having the opportunity to provide an evaluation of the supports. It was very likely that the additional support in place was provided insufficiently or inadequately. The intensity and adequacy of supports should to be investigated in future research, as suggested by Kyzar et al. (2012).

In sum, this study serves as an exploratory study guided by a conceptual framework for understanding family quality of life in Taiwan. As the conceptual framework illustrates, researchers should take other variables into consideration to increase knowledge related to family quality of life.

Future Directions

The study provides empirical evidence to document and understand the overall family quality of life of Taiwanese families and the intra-nation differences. The family quality of life conceptual framework provides an ecological perspective in interpreting the results.

Nevertheless, there are questions yet to be answered and asked in family quality of life for Taiwanese families for research, policy, and practice.

Future directions for research. First of all, researchers should examine national and international data to validate the family quality of life conceptual framework. A sound theory helps researchers to understand how input (i.e., family needs, strengths, and priorities) and systemic factors (i.e., societal values, policy, systems, and programs) interact with the influential factors and together impact the family quality of life outcomes. The knowledge can inform system decisions, enhance policy, and improve service to attain positive outcomes.

Second, there is a lack of studies examining family quality of life as an outcome of support and service delivery in the current literature (Kyzar et al., 2012). Researchers should continue to explore types (i.e., emotional, informational, instrumental, and physical) and sources (i.e., formal and informal) of support in terms of their impact on family quality of life. By doing so, researchers will be able to understand what affects family quality of life and how to identify strategies and resources to improve family quality of life accordingly.

Third, although there are studies verifying that family characteristics and parent participation do impact child outcomes in terms of academic achievement, emotional health, and behaviors (Davis-Kean, 2005; Epley, Summers, & Turnbull, 2011), more research is needed to confirm the connection between family quality of life and child outcomes.

Future directions for policy and practice. Having a conceptual framework and an instrument with reliability and validity not only aids in research but also helps identify those areas improvement that derive from Regulations of Services for Family Caregivers of Individuals with Disabilities (2012). First, policy leaders may choose to use family quality of life research data as one factor in determining who the beneficiaries of family support policy should be and in determining whether family support service-delivery systems are effective in enhancing families' quality of life in the judgment of the families. With respect to the issue of identifying beneficiaries, the finding that there is a discrepancy between family quality of life of families with higher and lower household income leads to the following questions: Are current government subsidies and services for families with lower household income adequate to enhance the families' quality of life? Related to the resource allocation issue is the one about efficiency: Are the family support regulations implemented as intended and, if not, why not and what changes in practice seem warranted based on data about implementation's effect on the intended outcome of enhanced family quality of life?

That question seems to flow logically from the law's mandates of program and service evaluation (Regulations of Services for Family Caregivers of Individuals with Disabilities, 2012). Given the properties of the Beach Center Scale, it seems that the agency administering the regulations or any independent evaluation agency could defend using the tools on a pre- and post-test basis to assess the effectiveness of specific interventions or services. Since it is already apparent that data from the tool evidence relatively lower satisfaction with Parenting and Emotional Well-being, it seems that the administering agency would be data-responsive if it were to bolster any existing services, or create new services, that are targeted on supports for families in these domains. Similarly, existing or, more likely, new data from the tool would inform policy makers about the allocation of fiscal and personnel resources to address high-need domains.

Conclusion

The family quality of life conceptual framework has implications for researchers, practitioners, and policy makers in understanding family outcomes within context of systemic, family-unit, individual-member, and support factors(Chiu et al., 2013; Zuna et al., 2010). This study uses the Beach Center Quality of Life Scale to document current conditions for Taiwanese families of children with intellectual disability and developmental delay. It explores and discusses Taiwanese families' ratings of satisfaction in the sequence from high to low: Family Interaction, Physical/Material Well-being, Parenting, and Emotional Well-being. Further, the study investigates differences among groups with various characteristics and found the family quality of life rating varies with different household income and the interaction between severity of disability and additional support at home. In closing, the study represents an initial effort in understanding family quality of life of Taiwanese families of individuals with disabilities. The findings suggest that family quality of life has the potential to be used as an indicator of positive outcomes in intervention evaluation, policy-making, and service delivery.

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CHAPTER 3: What Families Need: Validation of the Family Needs Assessment for Taiwanese Families of Children with Intellectual Disability and Developmental Delay

Abstract

This study documented the process of developing and validating the Family Needs Assessment (FNA), a 7-factor 73-item measure developed for research and practice. In developing the FNA, the research team identified a theoretical basis for family needs, used literature and qualitative results in generating items, ensured culturally and linguistically translation of the measure, and revised the measure based on results from pilot tests and cognitive interviews. Although a confirmatory factor analysis is necessary to support final validity, results from this study provide a foundation for understanding Taiwanese family needs. According to the results, the domains with highest needs are Hope (i.e., anticipating and achieving positive outcomes) and Disability-related Services (i.e., getting services and teaching the child with disabilities). The level of family needs varies across groups with different ages of child, severity of child's disability, and geographical location. Findings from this study indicate that the FNA, developed as a comprehensive, contemporary, accessible, and culturally appropriate tool, can contribute to the disability-related field in research and practice.

Chapter 3

What Families Need: Validation of the Family Needs Assessment for Taiwanese Families of Children with Intellectual Disability and Developmental Delay

Introduction

Disability-related research and policy recognize the importance of building family capacity to support child development (H. R. Turnbull, Beegle, & Stowe, 2001). The ethical principles and core concepts of disability policy hold belief that issues and challenges involving children are regarded as family concerns (H. R. Turnbull & Stowe, 2001). In 2003, 40 national organizations and nine federal agencies in the U.S. sponsored the National Goals Conference to explicate the "policy promises" that the U.S. had made to citizens with developmental disabilities, synthesize available research, and create a future research agenda (A. P. Turnbull et al., 2005). Of the 12 topical groups, family life was one of them. Representative stakeholders in the family life group, including self-advocates, family members, researchers, services providers, and agency administrators proposed the overarching goal related to family life as follows: "To support the caregiving efforts and enhance the quality of life of all families so that families will remain the core unit of American society" (A.P. Turnbull et al., 2005, p. 221).

Similar to the U.S., families of individuals with disabilities in Taiwan are legally entitled to appropriate supports and services. Article 51 in People with Disabilities Rights Protection Act (2011) states the following: "To reinforce the capability of the families to take care of people with disabilities, the municipal and county (city) competent authorities shall provide the services according to the results of need assessment."

To implement this Act, the first step in connecting the most appropriate support to families of children with disabilities is to explore family needs. Grotevant and Carlson (1989) found that professionals often collect information on family needs through observations, self-report surveys, and interviews. Among all methods, the self-report questionnaire with quantitative information was the most frequently employed in research studies for its appropriateness in measuring the subjectively-defined construct (i.e., family needs) and its time-efficiency in data collection (Creswell, 2009; Dillman, Smyth, & Christian, 2009). Although parents of children with disabilities have different preferences for written surveys as distinguished from face-to-face interviews, they generally have considered filling out a self-report family needs survey to be helpful in improving their communication with professionals (Bailey & Blasco, 1990; Sexton, Snyder, Rheams, Barron-Sharp, & Perez, 1991; Wang, 1993).

Family Needs Research

Family needs are characterized by the absence of support for a task that is important to the family, identified by one or more family members. The past literature, conducted in predominantly Western society, contains two lines of research: (a) areas with high needs and (b) factors influencing needs.

Areas with high needs. Parents tended to rate disability-related needs (i.e., services, respite care, daily care, education/teaching, and therapy programs) as areas with highest needs (Epley, Summers, & Turnbull, 2011; McConnell, Llewellyn, & Bye, 1997; Samuel, Hobden, LeRoy, & Lacey, 2012). Other areas with reported high needs include financial (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; Llewellyn, McConnell, & Bye, 1998; Palisano et al., 2010; Samuel et al., 2012), emotional (Brotherson et al., 2010; Freedman & Boyer, 2000), and physical health (Redmond & Rishardson, 2003; Snyder & Keefe, 1985), and social inclusion needs (Llewellyn et al., 1998; McCabe, 2008). Informational support, as compared to financial, emotional, and instrumental support, appears to be the type of support need most frequently cited by parents across countries (Ahmadi, sharifi, Zalani, bolouk, & Amrai, 2011; Almasri et al., 2011; Burton-Smith et al., 2009; Gu et al., 2010; Hsu & Lin, 2008; Lin, Qin, & Zhang, 2007).

Factors influencing needs. Although a greater number of studies focus on exploring family needs, some researchers have investigated patterns of family needs in groups of families with different child/family characteristics and correlations among demographics and family needs. The child/family factors identified in past studies are: (a) child's age, (b) severity of child's disability, (c) family socioeconomic status, and (d) geographical location.

- **Child's age** – Families who have older children have lower financial and childcare needs than do families with younger children (Bailey et al., 1999; Ellis et al., 2002). Related to different patterns of needs for families of children in different age groups, Wang (1993) found higher needs for informational and professional support in parents of elementary students as compared to parents of children under six. Hsu and Lin (2008) found that families of younger children reported higher medical care needs; families of older children reported higher needs related to their children's education.
- **Severity of child's disability** – Parents reported lower family needs if their children had less severe disabilities or if their children had better motor functions (Abelson, 1999; Bailey et al., 1999; Gu et al., 2010; Palisano et al., 2010).

Families also reported highest levels of unmet needs when children have multiple disabilities (Sloper & Turner, 1992; Wang, 1993).

- **Family socioeconomic status** – Studies have consistently found that families with fewer resources (i.e., racially/ethnically diverse group or low socioeconomic status) reported more intensive family needs (Epley et al., 2011; Farmer, Marien, Clark, Sherman, & Selva, 2004; Reyes-Blanes, Correa, & Bailey, 1999).
- **Geographical location** – Families in rural settings, as compared to urban settings, have reported higher financial needs and showed lower levels of awareness of needs and resources by choosing "not sure" for most items in the measure (J. Chen & Simeonsson, 1994).

Gaps in Family Needs Research on Taiwanese Families

Literature on family needs emerged in the U.S. in the late 1950s with an article describing six basic family needs: accepting disability, daily care, spirituality, financial, anxiety, and lifetime care (Murray, 1959). However, it was not until the 1980s that researchers began developing instruments in response to the requirement for identifying family needs mandated in the individualized family support plan by P. L. 99-457, the U.S. legislation incorporated as part of the Individuals with Disabilities Education Act and authorizing services to children age birth to three and their families. Despite emphases in research and policy, evidence-based approaches to identifying family needs, formulating action plans, and evaluating outcomes in practice are absent (C. Chiu et al., 2013; A. P. Turnbull, Summers, Lee, & Kyzar, 2007). Notably, the only measure validated and reported in a Taiwanese journal is the *Family Needs Questionnaire* (Wang, 1993).

There are two major gaps in family needs research relevant to Taiwanese families: (a) research in terms of the pattern of family needs and (b) whether the needs vary depending on different demographic factors is lacking. About 4.77% of Taiwan's 23 million citizens have disabilities (Department of Statistics at Ministry of Interior, 2012). Of these individuals, 96% of them live in their family homes. Biological or marital family members take care of about half of them. However, since most research centers on student achievement, the needs and well-being of Taiwanese family caregivers of individuals with disabilities are generally overlooked (W. Chen & Sun, 2008; Chou, Lee, Lin, Kröger, & Chang, 2009; Wang, 1993).Second, family needs measures have limitations in their comprehensiveness, accessibility, contemporariness, and cultural appropriateness.

- **Comprehensiveness** – In establishing reliability and validity of measures, most measures have been validated through psychometric evaluations (McGrew, Gilman, and Johnson (1992). The developers of these measures have tended to drop or group items based on statistical evidence; the process has produced shorter research measures with validity and reliability. A shorter measure has the advantage in decreasing response burden, but at the same time it produces risks of being less comprehensive.
- **Accessibility** – Since most measures were developed by researchers and have been available only through journal articles, the measures are not accessible to all families, practitioners, and researchers. Scholarly websites advertise the availability of some proprietary measures to be purchased for fees.

- **Contemporariness** – Walsh (2011) raised the issue that families have become increasingly diverse in many dimensions (i.e., forms, gender roles, relationships, culture, socioeconomics disparity, and family life course) during the past decade. However, there have not been updates in family needs measures, developed in the late 1980s and early 1990s, to address the needs of all contemporary families.
- **Cultural appropriateness** – Sufficient information supporting the accuracy of cultural and linguistic translations for tools has not been reported, and family needs tools have not been used on and validated for racially and ethnically groups other than European Americans (Bailey et al., 1999; Reyes-Blanes et al., 1999; Wang, 1993).

In summary, there should be comprehensive, accessible, contemporary, and culturally appropriate family needs measures for reporting family needs in Taiwan. This study describes the development and adaptation of a self-report measure, the Family Needs Assessment (FNA) for families in Taiwan. The purposes of the study are to report (a) the psychometric properties of the FNA, (b) family needs pattern for Taiwanese families, and (c) differences in family needs among various Taiwanese demographic groups. I address each purpose by answering the following research questions:

1. Is the Family Needs Assessment a valid and reliable tool in collecting data on needs of Taiwanese families of children with intellectual disability and developmental delay?
2. Do family needs vary among family groups with different child characteristics?

    a. Is there an interaction of the child’s age and severity of disability in regard to the total mean family needs scores?
    b. Is there a difference between the groups with younger and older children in regard to the total mean family needs scores?
    c. Is there a difference between the levels of the severity of child’s disability in regard to the total mean family needs scores?

3. Do family needs vary among family groups with different family characteristics?
    a. Is there an interaction of the household income and geographical location in regard to the total mean family needs scores?
    b. Is there a difference among groups with different household income in regard to the total mean family needs scores?
    c. Is there a difference among groups with different geographical location in regard to the total mean family needs scores?

Methods

Before this survey study, I applied for and received approval from the University of Kansas Human Subjects Committee. In the following sections, I introduce the scale development procedures, participant characteristics, measures, and data analysis plan.

Scale Development Procedures

In collaboration with families who have members with disabilities, researchers in the U.S., Spain, China, Taiwan, Turkey, and Colombia developed the FNA from 2010 to the present. I have been the Taiwanese representative on the international FNA team since its initial formation. I will review the major phases of the development of the FNA.

First, members of the international team reviewed the literature on research focusing on the assessment of family needs and grounded the scale in family systems theory as an aid to clarity and comprehensiveness in defining the construct to be measured (DeVellis, 2012). Table 5 covers the 11 theory-based domains of family needs, the domains' alignment with family systems theory, and a list of general questions for each hypothesized domain.

Table 5

Logical Domains of Family Needs

Logical Domain of Family Needs	Corresponding Domain from the Family Systems Theory	Item number in the survey	General Questions
Health	*Family Characteristics*	*#1, 12, 23, 34, 44, 53,61, 67*	Does the family need support to make sure that everyone stays healthy and gets care for health problems?
Family interaction	*Family Interaction*	*#8, 19, 30, 41,50, 59*	Does the family need support the get along together?
Lifespan changes	*Family Life Cycle*	*#5,27,38,47,56,64*	Does the family need support to transition to next life stage?
Daily care	*Family Functions*	*#2,13,24,35,45,54, 62,68,71*	Does the family need support to provide caregiving?
Recreation	*Family Functions*	*#3,14,25,36*	Does the family need support to play and have fun through leisure activities?
Social relationships	*Family Functions*	*#4,15, 26, 37, 46,63*	Does the family need support to develop relationships with others for the purpose of companionship and friendship?
Teaching	*Family Functions*	*# 6, 17,28,39,48,57, 65, 69, 72, 75, 76,*	Does the family need support to teach members what they need to know to be successful?
Getting services	*Family Functions*	*#7,18, 29, 40, 49, 58, 66, 70, 73*	Does the family need support to get education, social services, and health service?
Emotional health	*Family Functions*	*#9, 20, 31, 42, 51*	Does the family need support to deal with stress and takes care of emotional well-being?
Spirituality	*Family Functions*	*#10, 21, 32*	Does the family need support to engage in religious or spiritual practices
Economics	*Family Functions*	*#11,22,33,43,52,60*	Does the family needs support to manage finances?

Second, after reviewing available instruments and collecting qualitative data from parents (20 individual interviews and four cross-site focus groups), we developed an item pool and determined the measurement format.

Third, in addition to following DeVellis’ (2012) recommended steps in scale development, we summarized and adhered to recommendations of other survey development methodologists in creating the scale (Dillman et al., 2009; Fowler, 1995). We primarily used guidelines for developing ordinal closed-ended survey questions (guidelines 4.1-4.9, 5.20-5.27, and 6.3) to generate, edit, and arrange items (Dillman et al., 2009).

Fourth, we recruited five experts (two researchers and three family members) to review the items, administered items to a pilot sample, and re-evaluated items in the iterative process of scale development (DeVellis, 2012). The pilot tests took place across a two-month period and involved 50 responses across three sites (i.e., Spain, U.S., and Taiwan). The convenience sample was comprised of parents for this preliminary analysis to obtain social validity feedback to improve the FNA. Respondents in the pilot study, age 22 – 68, were mostly parents of school-age children or adults with intellectual disabilities (*n*=12) and autism (*n*=20). Most participants found the Pilot FNA useful (*n*=36, 72%) and indicated a perspective that its length was manageable in terms of the amount of time required to complete it (*n*=38, 76%). More than half the participants reported that they expected to take action to address needs they identified as a result of completing the FNA (*n*=26, 52%).

Since parents and researchers contributed to development of the FNA internationally, first drafts were in English. To cross-culturally adapt the FNA for participants in Taiwan, I used a back-translation method (Tassé & Craig, 1999) and adaptation procedures (Beaton, Bombardier, Guillemin, & Ferraz, 2000) comprised of four stages to ensure the linguistic and cultural equivalence (see Figure 3). The majority of the Taiwanese population speaks Mandarin (95%); Taiwan has a fairly low illiteracy rate (1.96% for citizens above 15). Hence, it is appropriate to translate into one language version for Taiwanese participants.

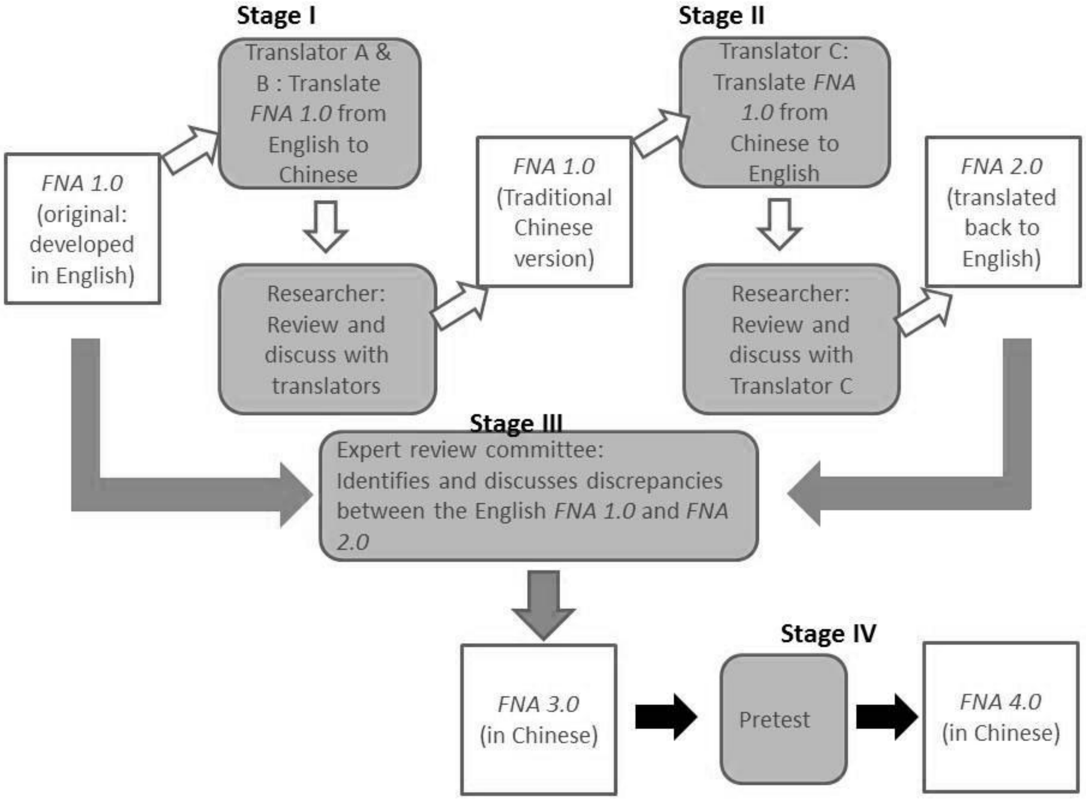

Figure 3. Translation and adaptation procedures for FNA.

The first two stages covered steps in translation and back-translation. In Stage I, two independent translators (Translator A and B), both of whom are native Mandarin Chinese with bilingual proficiency, translated the original FNA 1.1 into English. For Stage II, I recruited a back-translator (Translator C, a native English-speaker fluent in Mandarin Chinese and blind to the original version in English) to translate independently the synthesized translated FNA back to English. Translator C and I jointly prepared a copy of FNA 2.0 in English after reviewing the back-translated scale and written report.

The last two stages involved scale revision and piloting. In Stage III, I established an expert review committee consisting of the translators, a content expert, a methodologist, a parent leader, and a service provider. The committee provided recommendations for revisions to ensure semantic, idiomatic, experiential, and conceptual equivalence between the English and Chinese versions. Based on recommendations from the expert review committee, I produced FNA 3.0 in Chinese. Finally, five parents from Angel Heart Social Welfare Foundation in Taiwan completed the survey and made suggestions for Stage IV revisions. I prepared the final version, FNA 4.0 in Chinese, for use in this study.

I also conducted probe-approach cognitive interviews with five key parent informants to collect additional qualitative information to determine whether the questions were generating information as intended (Beatty & Willis, 2007; Dillman et al., 2009). I used retrospective probes to observe while each of the five parents completed the online survey and responded to my retrospective probes to identify unclear wording and instructions (Fowler, 1995). The five key parent informants included two fathers and three mothers who assumed leadership roles at a branch of a parent support group (i.e., Angel Heart Social Welfare Foundation). The key informants reported various educational levels ranging from high school to graduate degree. One of five parents described the family as a low-income household. Each of the five parents had a least one child with a disability (i.e., intellectual disability, physical disabilities, or autism; age 0-18). Based on their responses, I reworded several items to meet the reading levels of all

Taiwanese parents. One example is rewording the item “attending bowel and/or bladder management” into “helping my child go to the bathroom” in Mandarin Chinese.

Participants

To refine the FNA for Taiwanese families of children with disabilities, I recruited 500 parents of children with intellectual disabilities or developmental delays to complete mailed survey packets.

The Protection of Personal Information Act that was enacted in Taiwan in October 2012 made it impractical to compile a list and contact every parent who has a child with intellectual disability or developmental delay due to the inaccessibility to their personal information prior to consent. Therefore, I used convenience sampling strategies to recruit participants. First, I submitted research proposals to service agencies, parent leaders, and teachers from Taiwan’s four geographical regions to solicit their assistance in survey distribution. The nine-page proposal included a cover letter (brief overview of project, responsibilities/incentives for the collaborative agency, participant criteria), an introduction of myself as the researcher (including a short description of my identity as a sibling of a person with disability), a study timeline, a rationale for using the FNA, theoretical background and scale development, future plans for the FNA, and an overview of the web-based FNA survey with screenshots to demonstrate potential of FNA as an online tool in the future. Almost all local organizations committed to distribute the surveys, except for two organizations that declined due to other obligations during the proposed timeframe.

Next, I mailed 500 survey packets through Chunghwa Postal Service (equivalent to U. S. Postal Service) to service providers (e.g., social workers, teachers) who had agreed to work with me in survey distribution. These service providers, in turn, passed out the survey packets to parents and primary care providers. Each participant received a stamped self-addressed envelope that included the survey packet and an incentive of a gift card for 100 N.T. dollars (approximately three U.S. dollars) (Dillman et al., 2009). I was unable to send either a pre-notice postcards or reminder/thank you notes due to limited access to parents' contact information. Upon completion of the study, I prepared and distributed to all collaborative agencies a comprehensive report of the results and access to the refined scale, which is the revised FNA with items grouped by domains, in both web- and paper-format.

I received 409 completed surveys within four weeks of distribution for a return rate of 81.8%. Two graduate research assistants and I entered the responses into SPSS 20.0. Before answering the proposed research questions, I used SPSS 20.0 to perform data screening and compare demographic characteristics of the obtained sample with the overall Taiwanese census data. I conducted data screening before data analysis by examining distribution of items, identifying outliers, and imputing missing values when necessary (Tabachnick & Fidell, 2007). I used *the Social Welfare for People with Disabilities Report* (Department of Statistics at Ministry of Interior, 2012) as a reference and confirmed the sample's representativeness when compared to the population, .

After initial data screening, I removed eight cases that contained more than 15% missing data in FNA (did not respond to more than 11 items in the FNA section). The sample used in validating the FNA (research question 1) was comprised of 401 participants. Of this number, most were parents (289 mothers, 72.1%; 74 fathers, 18.5%) recruited through eight local early intervention centers, five parent support groups, and 11 schools. They ranged in age from 18 to

73 years (*M* = 41.38, *SD* = 8.10). The majority were non-aboriginal Taiwanese (91.5%, *n*=367). They were primary caregivers of children (260 boys, 138 girls) aged between 1 and 18 (*M* = 10.49, *SD* = 6.15). Approximately 73.1% of the children were diagnosed with intellectual disabilities (*n*=293) while the remainder had developmental delay diagnoses. Table 6 provides further information on participants. The original sample of 401 was reduced to 333 by 68 respondents who did not provide information as to one or more of the independent variables for research questions 2 and 3 (i.e., child' age, severity of disability, household income, and geographical location).

Table 6

Demographics (N=401)

	n	Percentage
Gender of the respondent		
Female	317	79.1
Male	84	20.9
Relationship to the child with disability		
Parent	363	90.5
Grandparent	11	2.7
Sibling	9	2.2
Other relatives nor non-relatives	18	4.6
Nationality (*n* =395)		
Taiwanese, non-aboriginal	367	91.5
Taiwanese, aboriginal	17	4.2
Chinese	11	2.7
Age group (*n*=371)		
Below 35	78	19.5
36-50	247	66.6
Above 51	46	11.5
Marital status (*n*= 387)		
Married/ living with a partner	322	80.3
Divorced or separated	40	10.0
Never married	20	5.0
Widowed	5	1.2
Employment status (*n*=385)		
Working full-time for pay or profit for a company or	163	40.6

family business		
Working part-time for pay or profit for a company or family business	42	10.5
Unemployed but looking for work	20	5.0
Not employed (e.g., stay-at-home, retired, public assistance pay)	160	39.9
Geographical location by administrative district (*n*= 391)		
Urban	168	41.9
Suburban	152	37.9
Rural	71	17.7
Geographical location by area (*n*= 391)		
Northern Taiwan	150	37.4
Southern Taiwan	138	34.4
Mid-Taiwan	57	14.2
Eastern Taiwan	46	11.5
Monthly household income (*n*= 368)		
Below 29,999 NTD	99	22.2
30,000~69,999 NTD	198	49.4
Above 70,000 NTD	71	22.7
Child’s Gender (*n*= 391)		
Female	135	33.7
Male	256	63.8
Child’s Age (*n*= 375)		
Younger child (0-6)	149	37.2
School age (7-18)	226	56.4
Severity of Child’s Disability (*n*= 364)		
Developmental delay	71	17.7
Mild intellectual disability	107	26.7
Moderate intellectual disability	105	26.2
Severe and profound intellectual disability	81	20.2

Note. Because of missing data, the percentages of some variables don’t add up to 100%. All cases were included for evaluating the FNA. The sample was reduced to 333 for the analyses of variance of child and family factors on family needs.

Measures

I designed and formatted the survey packet with common visual stimuli primarily using Dillman and colleagues (Dillman et al., 2009) guidelines (i.e., 6.6-6.10, 6.14-6.16, 6.21, 6.26, and 6.31) (Dillman et al., 2009). For example, I used consistent spacing, font type, font size, as well as color for an attractive visual presentation, an informative and interesting welcoming page, and response options horizontally aligned in one row. The survey included three parts: (a) FNA items, (b) Beach Center Family Quality of Life Scale (hereafter referred to as Beach Center Scale), and (c) demographic questions.

FNA. After the completion of scale development procedures described previously, I included 77 translated and culturally-validated items in Part 1 of the survey packet (Appendix A). The response stem enables respondents to indicate the level of need on a five-point likert-type scale (1-No need, 3- Need, 5- Very high need) in Part 1 of the survey. Since assessing validity and reliability of the FNA is the study's primary purpose, the items were not displayed in the theory-based 11 domains as they were in the Pilot FNA. Instead, I rearranged the order of items by presenting the first items from each of the 11 domains from the Pilot FNA in sequence, followed by the second items from each domain, until all 77 items were included.

Beach Center Scale. The concurrent validity measure, the Beach Center Scale (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006), is a 25-item five-factor quantitative scale, translated and validated on a Chinese sample (Hu, Wang, & Fei, 2012). Arguably, Taiwan and China share many similarities in traditional values and languages (Chan & Lee, 2004). I determined that it would be appropriate to adopt the Chinese Beach Center Scale with minimal changes in written text (i.e., from Simplified Chinese to Traditional Chinese) and wordings (e.g., change from 'handicap' to 'disability') for Taiwanese families. The five factors of the scale include: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-related Services. The satisfaction rating from the Beach Center Scale has an acceptable internal consistency (α= .88), test-retest reliability (.60- .77), and fit for the sub-scale level model for Chinese families (χ^2 (265, n=442) = 748.15, $p < .001$, CFI = .97, RMSEA =

.066). However, two of the FNA domains are conceptually an expansion of the Disability-related Services domain in the Beach Center Scale; thus, the inclusion of that sub-scale would be tautological. Therefore, I examined from the first four domains.

Demographic questions. The survey included polychromous questions on information of the respondents and their children with disabilities. I also revised the demographic questions in the Taiwanese pilot study to reflect country-specific questions (e.g., family income is converted into N.T. dollars, zip code is changed to a list of counties/cities) based on parents' responses from the pilot tests and cognitive interviews.

Data Analysis

To answer the research questions, I first conducted factor analysis, internal consistency tests, and correlational tests with the concurrent validity measure (Beach Center Scale) to ensure construct validity and reliability of the FNA. Then, I reported results of the total sample and by demographic groups. Finally, I performed two between-subjects ANOVAs on the dependent variables (total mean scores of FNA) (Tabachnick & Fidell, 2007) to examine whether family needs vary in groups with different child and family factors.

Psychometric analyses for the FNA. To obtain results on validity, I performed an exploratory factor analysis (EFA) of the FNA to determine the measure's simplest and most coherent structure. I analyzed the complete scale data using Principal Axis Factoring because factors were considered underlying processes that produce associations (Salkind & Green, 2011). I used three criteria to determine the number of factors to rotate: (a) the eigenvalue, (b) visual inspection of the scree plot, and (c) interpretability of the factor solution. I considered only factor loadings above .32 salient (Comrey & Lee, 1992). Next, I examined the criterion validity of the

FNA in terms of covariations between the FNA subdomain scores with the corresponding Beach Center Scale subdomain mean scores (Salkind & Green, 2011). Theoretically lower family needs should correlate with higher family quality of life scores; therefore I expected negative correlation between the two constructs. Last, I assessed internal consistency of each factor with estimate of coefficient alpha to ensure each domain contains questions with Cronbach's alpha above .80 (Frey, 2006).

After I obtained the structure, I reported descriptive results in total mean score and domain scores and further examined if the ranking of family needs domains was consistent across groups with different child and family characteristics.

Family needs group difference- Child characteristics. The 2x3 two-way analyses included examining a two-way interaction effect (child's age x severity of disability) and two main effects (child's age and severity of disability) on family needs score. To determine *Child's Age*, I first calculated age of the child with disabilities by using the reported date of birth and Feb 12, 2013 as a reference day. The cases were divided into two groups (1- child age younger than 6 years; 2- school-age children). The *severity of disability* for the child's disability, diagnosed by a multidisciplinary team, was documented on the official record on the government issued disability identification card. Respondents originally reported in five categories, the first two (developmental delays and mild intellectual disability) were combined into one group (1-mild), moderate remained the same (2-moderate), and the last two (severe and profound) were combined into one group (3-severe). I performed Fisher's Least Significant Difference (LSD) post-hoc tests to further investigate significant main effect(s)/ interaction. The level of statistical significance was set at $p < .05$ for all tests.

Family needs group difference- Family characteristics. Following similar procedures mentioned in the preceding section, I performed a 3x3 two-way ANOVA, including an interaction effect (household income x geographical location) and two main effects (household income and geographical location) on family needs score. The 3-level *household income* was derived from the question on the monthly household income (1- below 29,999 NTD, 2- 30,000 to 69,999 NTD, and 3- above 70,000 NTD). Finally, *geographical location* was based on the city or county in which the respondents lived. The value was recoded into three categories (1-urban, 2- suburban, 3- rural) based on the calculation of an urbanization index (M. Chiu, Han, Hong, Bei, & Zhang, 2010; Teng & Huang, 2004).

Results

Prior to analyses, I examined responses of the 77 FNA items through various SPSS programs for accuracy of data entry, outliers, and missing values. As mentioned in the methods section, I deleted eight cases with more than 15% missing data, leaving 401 cases for analysis. I used EM (expectation maximization) estimation to impute the missing values in the FNA because the MCAR test was statistically significant ($\chi^2(5097)=5789.322$, $p<.01$). After exploring the data, I further examined univariate and multivariate outliers by identifying potential outliers from the Box’s plot. No outliers remained after data screening.

Psychometric Analyses for the FNA

A principal axis factor analysis employing Promax rotation was used to discern the factor structure of the scale. The correlation matrix of item scores was factored with unities in the diagonal, and factors with eigenvalues exceeding 1.0 were retained for rotation. I determined factor membership based on a factor loading of .32 or greater and removed four items (#23, #44,

#51, #53) with loadings smaller than .32 on every factor after further examination on content. Among the remaining 73 items, 19 items cross-loaded on more than one factor. I reviewed each loading and item content to determine the membership and label of the factor. After deciding the membership of items and examining the factor correlation matrix (Table 7), I decided to retain only the first seven factors because factor 9 and 10 contained zero items. Factor 8 contained item #77, which was then re-loaded on factor 1 because of the acceptable loading (.35). Additionally, the three factors were not strongly correlated with the first seven factors.

Table 7

Factor Correlation Matrix

Factor (*Numbers of items*)	2	3	4	5	6	7	8	9	10
1 (*26*)	.649	.692	.580	.657	.580	.625	-.272	.064	.324
2 (*13*)		.524	.417	.534	.536	.503	-.195	.206	.361
3 (*12*)			.543	.530	.594	.548	-.081	.016	.360
4 (*5*)				.208	.448	.461	.028	.046	.194
5 (*7*)					.387	.453	-.251	-.140	.386
6 (*6*)						.477	-.220	.254	.408
7 (*5*)							-.299	.075	.312
8								-.040	-.110
9									.159

Note. Item 77 was reloaded on factor 1

The results yielded a 7-factor solution that, taken together, accounted for 63.61% of the variance. The factors were strongly correlated with each other (.50 to .85). Factor 1 (Disability-related Services) accounted for 46.58% of the variance and contained primarily the 26 items related to services and teaching specifically for the child with disabilities. Factor 2 (Caregiving) accounted for 4.67% of the variance and contained 13 items related to daily care activities and teaching daily living skills. Factor 3 (Social Connection) accounted for 3.36% of the variance and contained 12 items related to interacting within and outside of the family. Factor 4 (Hope) accounted for 3.12% of the variance and contained five items related to positive emotion and progress. Factor 5 (Family Resources) accounted for 2.21%, of the variance and contained seven items on using resources such as technology and transportation to access and secure healthy life in home, community, and school. Factor 6(Economics) accounted for 2.00% of the variance and contained six items related to paying and saving money for present and the future. Factor 7 (Recreation) accounted for 1.29% of the variances and contained five items such as participating in preferred and enjoyable activities. Table 8 summarizes the results with factors assigned labels indicative of their content (See Appendix B for the complete factor loading table). Coefficient alpha computed from the correlation among the 73 items was .98 and ranged from .85 to .97 for the seven factors.

Table 8

Item Loading on Factors

Factors	Loading
Factor 1. Disability-related Service	
73.Feeling informed and helped by teachers about the improvement and the difficulties of my child(ren)	.994
72.Teaching appropriate behavior	.973
74.Teaching communication skills	.970
69.Teaching social and emotional skills	.846
40.Having a trusting partnership with professionals	.805
66.Knowing and acting on my child(ren)'s educational rights	.755
76.Teaching my child(ren) about sexuality	.682
49.Monitoring services to make sure that they are beneficial	.656
39.Teaching choice-making and problem-solving	.655
70.Getting information necessary to make sound decisions about services	.615
17.Helping my child(ren) reach goals during every day routines	.561
41.Establishing close emotional bonds among members of the family	.556
71.Feeling supported by professionals to manage the difficulties associated with daily living.	.554
38.Planning for my child(ren)'s successful transition from preschool to primary school or from primary school to secondary school	.547
48.Teaching safety in the home and other places	.545
29.Having access to necessary services, such as speech therapy, physio/physical therapy, orientation and mobility, occupational therapy, audiology, and nursing care	.543
47.Developing long-term goals for family members	.509
46.Responding to negative situations and attitudes (e.g., bullying, teasing, staring) to all family members	.505
64.Planning for the future after I'm no longer able to take care of my family members	.463
42.Having support from other families who have a child with disabilities	.430
28.Knowing when my child(ren) is making progress	.380
50.Being flexible as a family in making changes when they are needed	.372
58.Making changes in services when necessary, even when professionals disagree	.363
77.Helping with homework	.351
20.Managing stress	.346
12.Coordinating medical care among two or more physicians	.329
Factor 2. Caregiving	
13.Going to bathroom	.983
2.Attending to daily care activities (e.g., bathing, brushing teeth, dressing, eating)	.842
65.Teaching child(ren) to attend to toileting needs	.832
35.Getting regular and special resources (such as technology equipment and materials, adapted switches, special foods) needed by family members	.677
24.Giving medications	.669
57.Teaching independent living skills (such as eating and dressing)	.571
75.Teaching motor skills (e.g., riding a bike, walking, climbing stairs)	.549
34.Having appropriate care for hearing related needs	.536

68.Ensuring that home and community settings are accessible	.498
45.Getting child care	.448
16.Getting new childcare	.446
54.Having a break from caretaking (such as respite care)	.330
1.Monitoring health conditions (having a regular doctor/ health checks)	.327
Factor 3. Social Connection	
32.Understanding my family members' challenges within my family's spiritual beliefs.	.744
31.Enhancing each family member's self-esteem	.728
37.Helping all family members to know how to respond to questions about disability	.624
26.Helping my family members make friends	.584
21.Teaching my child(ren) about spiritual beliefs	.569
36.Doing relaxing things/activities at home	.509
30.Solving problems together	.487
15.Helping my family members (e.g., neighbors, friends) in socializing with others	.466
27.Moving within the same community or to a different community	.462
4.Helping others (e.g., neighbors, friends) in knowing how to socialize with my family members	.455
10.Having a spiritual community that includes my child(ren)	.452
19.Talking about feelings, opinions, and challenges with all members in my family	.365
Factor 4. Hope	
7.Having educational services where my child(ren) are making progress	.820
8.Having a clear understanding of each family member's strengths and needs	.796
9.Feeling hope about the future for our family members	.796
5.Feeling supported by professionals at the time of learning about my child(ren)'s disability	.657
6.Participating in goal-setting to enhance family members' learning	.625
Factor 5. Family Resources	
63.Using technological communications (such as email, Facebook) to connect socially with others	.776
62.Having appropriate transportation	.599
59.Providing supports to include all members of my family in family activities	.547
56.Starting a new school year	.536
67.Preventing substance abuse and other addictions (e.g., alchohol, drugs)	.412
61.Having healthy life style(such as healthy diet/ exercising)	.374
Factor 6. Economics	
11.Paying basic needs (such as food, house, clothing)	.689
22.Paying school fees and/or child care (baby-sitter)	.662
43.Saving money for the future	.580
52.Getting or keeping a job	.396
33.Paying for special therapies or equipment for my child	.396
60.Applying for government benefits and addressing government benefit denials	.396
Factor 7. Recreation	
3.Participating in preferred indoor community recreational activities (e.g., movies, concerts, art classes)	.582

14.Participating in preferred outdoor community recreational activities (e.g., swimming, playing ball, playing in the parks)	.579
25.Going on family vacations	.498
55.Participating in social occasions with friends, co-workers, or others	.398
18.Having appropriate extracurricular / holiday care	.379

Note. Items removed due to low loadings on factors: 23.Having appropriate vision and eye care; 44.Having appropriate dental care; 51.Dealing with challenges related to all family members; and 53.Getting a full night's sleep.

I examined the criterion validity of the FNA in terms of co-variation between the factor scores and subdomain scores of the Beach Center Scale. One of the seven factors, Economics, was significantly related to Physical Well-being (r = -1.45, p< .01), Emotional Well-being (r= -1.06, p<.05), and the total score (r = -1.14, p<.05) in the Beach Center Scale.

The factors reflecting the greatest expressed needs were Hope (M=3.42. SD= .87) and Disability-related Services (M= 3.12, SD= .85). This pattern, as displayed in Table 9, was consistent across most groups with different family and child characteristics (i.e., child’s age, severity of disability, household income, and geographical location). However, for families with lower household income, Economics was the area with highest reported family needs (M= 3.30, SD= 1.00).

Table 9

FNA Domain Descriptive Information (N=401)

Factor	1	2	3	4	5	6	7
	Disability-related Service	Caregiving	Social Connection	Hope	Family Resources	Economics	Recreation
Number of items	26	13	12	5	7	6	5
Cronbach's Alpha	.968	.927	.937	.901	.863	.880	.846
Mean(SD)	3.12(.85)	2.52(.95)	2.65(.85)	3.42(.87)	2.55(.91)	2.98(.99)	2.81(.89)
Rank order	2	7	5	1	6	3	4
Domain Mean Score by Subgroup (*N*=333)							
Child's age							
Younger (*n*=129)	3.19(.77)	2.64(.84)	2.72(.78)	3.50(.83)	2.82(.76)	3.03(.96)	2.61(.82)
School Age (*n*=204)	3.09(.90)	2.47(1.05)	2.64(.91)	3.39(.89)	2.52(.96)	2.99(1.05)	2.83(.97)
Severity of Disability							
Mild (*n*=162)	2.97(.80)	2.25(.84)	2.54(.80)	3.31(.85)	2.36(.80)	2.80(.92)	2.63(.80)
Moderate (*n*=95)	3.31(.87)	2.56(.98)	2.78(.87)	3.58(.89)	2.72(1.02)	3.09(1.10)	2.95(.91)
Severe (*n*=76)	3.26(.89)	3.13(.98)	2.81(.93)	3.52(.86)	2.78(.90)	3.34(.99)	3.08(.99)
Household Income							
Lower Income Families (*n*=80)	3.17(.97)	2.62(.97)	2.71(.95)	3.26(.97)	2.68(.98)	3.30(1.00)	2.78(.92)
Medium Income Families (*n*=176)	3.13(.85)	2.53(.99)	2.80(.93)	3.46(.85)	2.55(.90)	3.03(1.00)	2.63(.85)
Higher Income Families (*n*=77)	3.10(.72)	2.45(.95)	2.71(.79)	3.53(.80)	2.44(.82)	2.63(.96)	2.91(.80)
Geographical Location							
Urban (*n*=141)	3.26(.89)	2.69(.92)	2.78(.90)	3.60(.80)	2.69(.95)	3.10(1.05)	2.96(.91)
Suburban (*n*=132)	2.93(.80)	2.20(.99)	2.52(.83)	3.26(.84)	2.34(.83)	2.77(.95)	2.61(.87)
Rural (*n*=60)	3.27(.80)	2.93(.85)	2.75(.80)	3.40(.80)	2.73(.86)	3.31(.96)	2.97(.84)

The factors rated as relatively lower needs were Family Resources (*M*= 2.55, *SD*= .91) and Caregiving (*M*= 2.52, *SD*= .95*)*. Table 5 shows this pattern that was consistent with most groups with the exception of families of children with severe/profound disabilities. This group of families reported Caregiving as the third highest area of needs (*M*= 3.13, *SD*= .98). Notably, families of children with severe/profound disabilities generally reported higher needs in all domains.

Family Needs Group Difference - Child Characteristics

Table 10 reports descriptive data (i.e., mean and standard deviation) for each group by its child characteristics. I performed a 2x3 between-subjects ANOVA on the total mean score of 73 items, with higher FNA mean scores indicating higher family needs. Results from the Levene's test of equality of error were not significant at *p*<.001, showing that homogeneity of variance across groups was equivalent.

Table 10

Descriptive Statistics of Child Factors (N=333)

Variable	*M(SD)*
Child's Age	
Younger children (*n*=129)	2.95(.70)
School age children (*n*=204)	2.85(.70)
Severity of Disability	
Mild (*n*=162)	2.70(.72)
Moderate (*n*=95)	3.01(.82)
Severe (*n*=76)	3.13(.84)

As summarized in Table 11, the family needs varied significantly with child's age, *F*(1, 327)=5.437, *p*<.05. However, the strength of the relationship with child's age and family needs was weak with partial η^2=.02. Additionally, family needs varied significantly with severity of the child's disability, *F*(2, 327)=11.446, *p*<.01. However, the strength of the relationship with child's age and family needs was moderate with a medium effect size (partial η^2=.07). The LSD post hoc tests consisted of all pairwise comparisons among the two age groups and three levels of disability severity. Results showed that families of younger children tend to report higher family needs, as compared with school-age children (*p*=.02). It also revealed that families of children with severe/moderate disability reported higher family needs as compared to families of children with mild disability (*p*<.001), but the difference between families of children with severe disability and families of children with moderate disability was not statistically significant (*p*=.82).

Table 11

Analysis of Variance of Child Factors on Family Needs (N=333)

Source of Variance	SS	df	MS	F
Child's age	3.178	1	3.178	5.437*
Severity of disability	13.383	2	6.692	11.446**
Child's age x Severity of disability	.741	2	.370	.634
Error	191.170	327	.585	

Note. * $p < .05$, ** $p < .01$

Family Needs Group Difference - Family Characteristics

Table 12 reports descriptive data (i.e., mean and standard deviation) for each group by its family characteristics. Results from the Levene's test of equality of error was not significant at *p*<.001, showing that homogeneity of variance across groups was equivalent.

Table 12

Descriptive Statistics of Family Factors (N=333)

Variable	*M(SD)*
Household Income	
Lower income families (*n*=80)	2.94(.87)
Medium income families (*n*=176)	2.89(.80)
Higher income families (*n*=77)	2.84(.70)
Geographical Location	
Urban (n=141)	3.02(.81)
Suburban (n=132)	2.67(.77)
Rural (n=60)	3.07(.71)

As summarized in Table 13, the family needs varied significantly with geographical location, $F(2, 324)=8.096$, $p<.05$, with a small effect size (partial $\eta^2=.05$). No statistically significant main effect of household income was found; nor was there a significant interaction between geographical location and household income. The LSD post hoc pairwise comparison among the three groups of geographical location showed families in urban and rural areas have higher needs than families in suburban areas ($p<.001$). However, there was no statistically significant difference between families in urban and rural areas ($p= .50$).

Table 13

Analysis of Variance of Family Factors on Family Needs (N=333)

Source of Variance	SS	df	MS	F
Household income	.057	2	.029	.048
Geographical location	9.756	2	4.878	8.096*
Household income x Geographical location	2.854	4	.713	1.184
Error	195.218	324	.603	

Note. * $p < .05$, ** $p < .01$

Discussion

This study sought to validate the FNA and report needs of Taiwanese families of children with intellectual disabilities in answering research questions on (a) psychometric properties of the FNA, (b) group differences in families with various child age and severity of disability, and (c) group difference in families with various levels of household income and geographical locations. In the following sections, I discuss limitations of the study, connect results from the analyses to family literature, and propose future directions of the FNA in research and in practice.

Limitations

This study includes two primary limitations. First, there are concerns in the external validity in generalizing findings to all family members with children with intellectual disability and developmental delay. Although I found the demographic characteristics (i.e., marital status, employment status, household income, and geographical location) representative for the population, it was impossible to analyze responses of non-respondents who were not willing to participate in the study. Additionally, using responses from only one family member, who usually is the most-involved caregiver in the family, inevitably poses methodological challenges to the study. Whether the responses are representative for the family unit remains unclear. Nevertheless, the responses from the most-involved family members, being the members who oversee family routines, provide more realistic accounts on needs for the whole family.

Second, there are concerns in validity of the FNA. It is necessary to perform a confirmatory factor analysis (CFA) to support the construct validity because (a) correlations between the FNA and the concurrent measure (i.e., Beach Center Scale) were not satisfactory except for the domain of Economics (see further discussion in Chapter 4), and (b) items were eliminated and reloaded in the final scale. However, the limited sample size (*N*=401) was not adequate to perform two factor analyses. Therefore, there was a limitation in establishing validity for the FNA with its 73-item and 7-factor.

Analysis of Results and Family Literature

Psychometric analyses for the FNA. Despite these limitations, however, this initial validation study indicated evidence of construct validity and reliability for the 73-item FNA. Based on participants' responses to the FNA, family needs can be grouped into seven factors: Disability-related Services, Caregiving, Social Connection, Hope, Family Resources, Economics, and Recreation. It is, however, necessary to recruit a new sample for a confirmatory factor analysis (CFA) to expand the usability and increase validity of the FNA.

In addition to establishing validity and reliably for the FNA, the study provided a foundation for understanding family needs in Taiwan. Among the seven factors, participants reported highest need in the Hope and Disability-related Services domains. This finding is consistent with the trend in disability-related studies that has focused on positivity and getting services to support families to achieve positive goals (C. Chiu et al., 2013; A. P. Turnbull et al., 2007). Relatively, Caregiving and Family Resources were the domains with lowest reported needs. The findings can be explained by values and traditional beliefs in Taiwan that families are responsible to take care of family members and potential additional support at home from extended family members (Chou et al., 2009; Department of Statistics at Ministry of Interior, 2012).

The domains with highest and lowest ratings were generally consistent across groups with different child and family characteristics with two reasonable exceptions: Families with lower household income reported highest needs in Economics (Epley et al., 2011), and families of children with severe/profound intellectual disability reported higher needs in Caregiving (Palisano et al., 2010; Samuel et al., 2012).

Family needs group difference – Child characteristics. Further examination of child and family factors revealed severity of child's disability and age as statistically significant determinants for expressed needs. Consistent with past studies, families of younger children reported higher family needs than families of school-age children (Bailey et al., 1999; Ellis et al., 2002; Wang, 1993). This finding might be anticipated because families of younger children with intellectual disabilities or developmental delays would have less experience navigating the system and more caregiving responsibilities in contrast to families who have an older child, as proposed in the studies cited above. The explanation of more intensive caregiving responsibilities also applied to severity of disability. Families of children with moderate and severe/profound intellectual disabilities expressed higher family needs as compared to families of children with developmental delays and mild intellectual disabilities (Abelson, 1999; Bailey et al., 1999; Gu et al., 2010; Palisano et al., 2010).

Family needs group difference – Family characteristics. Contrary to the findings from previous studies, I did not find family household income to be a significant determinant of family needs (Epley et al., 2011; Farmer et al., 2004; Reyes-Blanes et al., 1999). One possible explanation was that the income-needs ratio should be taken into consideration when examining impact of household income on family needs. Unfortunately, I identified extensive inaccuracy in responses on the question of number of people supported on household income and was not able to calculate financial resources available for each person.

Another interesting finding was that families in urban and rural areas reported statistically significantly higher family needs than families in suburban areas. Past studies have found that more advanced urbanization has been associated with a greater risk for depression, potentially due to the higher level of stress (Liao et al., 2012). One previous study in China reported that urban families, as compared to rural families, were more certain in expressing their needs and attributed it to higher level of awareness in services (J. Chen & Simeonsson, 1994). It is defensible to interpreted these findings to mean that the higher stress in combination with higher level of awareness in disability rights/services might contribute to the higher levels of needs expressed by urban families. Unlike previous studies that usually compared rural to urban areas, the dissertation study compared three groups with various levels of urbanization. Two questions remain unclear: First, why were there no significant differences in levels of family needs between urban and rural families? Second, why did suburban families report lower needs than urban and rural families? Further investigation of the level of urbanization and family needs is warranted.

Future Direction for the FNA

The FNA was a joint effort among professionals and families across nations. Through this initial validation study, I present a tool that offers opportunities for researchers to understand family needs and propose future directions of the FNA for research and for practice.

Future directions for research. For research, I recommend that researchers (a) recruit a larger and more diverse sample, (b) collect cross-cultural data to investigate similarities and differences among various nations, and (c) examine effectiveness of the FNA as an intervention tool.

First, a second wave of data collection in Taiwan is necessary to confirm the proposed factor structure that may explain the underlying construct of family needs. With a larger and more diverse sample, it is possible to explore how other factors (e.g., other additional disabilities, available resources) impact family needs and to generalize the findings to a larger population. Ideally, all family members should participate in the process of identifying family needs in a family meeting. However, there are cultural differences in how comfortable and open people are to speak in front of other family members. I recommend that future investigators include multiple family members in identifying family needs in a culturally appropriate manner.

Second, the FNA research team aims to develop a truly culturally appropriate international family needs measure. Therefore, the research team will recruit participants from Spain, China, Taiwan, Columbia, and Turkey. It is expected that more researchers from other countries will join the international effort in the future. The international data will offer a global understanding of family needs between and within nations.

Third, using the FNA to identify and prioritize family needs may lead to enhanced family-professional partnerships, enhanced family well-being, and ultimately, improved child outcomes. Future research should examine the tool's effectiveness as part of an intervention in improving family and child outcomes.

Future directions for practice. The FNA contributes to the field in practice at individual, and program/system levels. For individual families, the FNA tool has the potential to assist families and professionals to take action at an individual level and assist service providers to understand family needs at a group level. During a problem-solving process, the FNA can be used with flexibility: online or paper-based, self-administered or jointly completed by families and professionals, complete all domains or choose specific domains. The design of the FNA allows respondents to identify and prioritize family needs and even obtain an individual family needs report upon completion of the FNA. Using the FNA results, families and participants can jointly develop an action plan to address the needs. The FNA will be hosted online for the use of families and professionals once the satisfactory validity is obtained.

I presented the information about resources distribution in Chapter 1. In the introduction, I further stated that implementation of the People with Disabilities Rights Protection Act (2011) requires connecting resources to families based upon their needs. Arguably, just as there is an ethical principle that holds that families are the core units of society, there is another ethical principle known as equity. Under the principle of vertical equity, because these families with the greatest needs are more likely to remain intact when greater resources are allocated to them, these families should have priority claims upon resources. At a system level, the results from the needs assessment affect decision-making in allocating financial resources among families who have members with disabilities. The practice of allocation cannot be decided defensibly without collective family needs data derived from a tool such as the FNA. Thus, the data-driven decision-making process should be connected to family support policy.

Conclusion

Despite the fact that the family quality of life conceptual framework (C. Chiu et al., 2013) situates disability within an ecological model and recognizes that societal values have a bi-directional interaction with family systems, there have been relatively few studies reporting needs for families with other ethnic backgrounds as compared to families with European roots. Moreover, Tassé and Craig (1999) cautioned that factors such as social expectation for age and gender, family structure, communication styles, and attitudes toward disability should be taken into account in cross-cultural measure validation. Only a few studies have highlighted the cultural aspect of family needs. Even fewer publications have focused on Asian populations, despite the fact that this group differs excessively from families with European roots in beliefs, values (i.e., collectivism and credentialism), and life experiences (Chan & Lee, 2004).

This study documented the development and validation process of the FNA, a 7-factor 73-item measure developed for research and practice. In developing the FNA, the research team identified a theoretical basis for family needs, used literature and qualitative results in generating items, ensured culturally and linguistically translation of the measure, and revised the measure based on results from pilot tests and cognitive interviews. Although a confirmatory factor analysis is necessary to support final validity, results from this study provide a foundation for understanding family needs in Taiwan. I identified seven domains from the study: Disability-related Services, Caregiving, Social Connection, Hope, Family Resources, Economics, and Recreation. According to the results, the domains with highest needs are Hope (i.e., anticipating and achieving positive outcomes) and Disability-related Services (i.e., getting services and teaching the child with disabilities). The level of family needs varies across groups with different ages of child, severity of child’s disability, and geographical location. Findings from this study indicate the FNA, developed as a comprehensive, contemporary, accessible, and culturally appropriate tool, can contribute to the disability-related field in research and in practice.

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CHAPTER 4: Revisiting the Conceptual Framework: Research Agenda

Abstract

This dissertation uses the family quality of life conceptual framework to report and discuss family quality of life and family needs related to Taiwanese families. The findings provide feedback in refining the conceptual framework. In this chapter, I present potential reasons of non-correlation between family needs and family quality of life domain scores. Further, I propose an updated conceptual framework and relevant research questions.

Chapter 4

Revisiting the Conceptual Framework: Research Agenda

Introduction

This dissertation contributes to family literature in three ways. First, the study provides evidence that both the Beach Center Quality of Life Scale (The Beach Center Scale) and the Family Needs Assessments (FNA) are practical tools for Taiwanese family. Second, it provides a foundation to expand the knowledge in family needs and family quality of life. Third, guided by the conceptual framework, the misalignment between hypotheses and findings in the study offers possible areas for refinement in the conceptual framework.

From the conceptual framework, I hypothesized that there will be a negative correlation between the family needs and family outcomes. Thus, I selected the Beach Center Scale as the concurrent validity measure in validating the FNA. Unexpectedly, results from the dissertation study countered the hypothesis. Among the seven factors, only one (Economics) was negatively correlated with the total scores and two domain scores (Physical Well-being and Emotional Well-being) at a .05 level of significance.

To conclude this dissertation, I present potential reasons of non-correlation between family needs and family quality of life domain scores. Based on this discussion, I propose an updated conceptual framework and a relevant research agenda.

Possible Explanations of Non-correlation

I identify two approaches to explain the non-correlation between total/domain mean scores of the FNA and the Beach Center Scale. First, the relationship between the two constructs based on an initial theory framework and limited literature may need refinement. Second, the two selected measures may not accurately reflect the two constructs.

Limited Support of the Hypothetical Relationship

The hypothesis of the correlation between the two constructs was largely based upon the conceptual framework, which was derived from general family literature, family quality of life literature, and researchers' assumptions. The conceptual framework proposes a model with a variety of factors that interact with family needs. Therefore, it is important to recognize that the correlation may be influenced by family strengths and other systemic, family-unit, individual member, and support factors.

Additionally, the two constructs may not have a linear relationship. Perhaps the relationship is influenced by other immediate outcome variables. One recent study conducted in an early intervention setting revealed that families with minimal perceived needs (fewer than two perceived needs, as measured by the Early Childhood Services Survey) had better immediate family outcomes (mean scores from the Family Outcomes Survey) as compared to those with high perceived needs (7 or more perceived needs) (Epley, Summers, & Turnbull, 2011). The authors then used *perceived needs* as a covariate in a regression analysis and concluded that parents' satisfaction of services predicts immediate family outcomes and the broader family quality of life outcomes. Because of the limited literature on both family needs and family quality of life studies, the initial theory needs further refinement when more studies become available.

Measurement Issues

On the assumption that a linear correlation exists between family needs and family quality of life, I discuss other potential issues in measuring the constructs. The purpose of scale development is measure latent variables to understand a construct or an underlying phenomenon (DeVellis, 2012). Ideally, the relationships between instruments correspond with relationships between latent variables – family needs and family quality of life in this study. However, the lack of correlation among the majority of domain and total scores from the two measures may be due to (a) subjectivity in measures, (b) applicability of items, and (c) unparalleled domains.

First, both tools measure the subjective perception of one family member. Inevitably, the perceived family needs and family quality of life from one family member's perspective may not reflect the hypotheses of negative correlation between the two constructs. For example, perhaps a mother who is an advocate considers many items from the FNA with very high needs, but because she is able to identify and address the needs, she reports very high family quality of life. On the contrary, Chen and Simeonsson (1994) found that rural families tend to report *not sure* on most items, so a mother can have low family quality of life and low family needs score, assuming that her family has no needs in most items. Those scenarios illustrate possible cases that would lead to the findings in the FNA study.

Chen and Simeonsson's study brings up the second issue of item applicability. In the dissertation, I used two 5-point Likert-type scales. Family respondents might be forced to choose among five options (from 1- *very dissatisfied* to 5- *very satisfied* in the Beach Center Scale; from 1- *no need* to 5- *very high need* in the FNA) even when the items were not applicable or meaningful to them. Adding the options of "*not sure*" or "*not applicable*" may decrease the sample size with valid responses, but it would provide more accurate and authentic information.

Third, the FNA research team generated items and grouped the items into different domains according to factor loadings. Most family needs domains did not directly correspond to one or more specific family quality of life domains. In particular, there is a dominant factor in the FNA (Disability-related Services). The unequal item distribution across domains and misalignment between domains conceptually could be problematic when examining correlations.

Implications for Conceptual Framework and Future Research

Taken together, I propose an updated family quality of life conceptual framework. As shown in Figure 4, I made several changes to increase the framework's clarity and validity.

First, I simplified input to *family strengths and needs* to avoid redundancy in the original statement (i.e., *new family strengths, needs, and priorities*). Next, I added *support outcomes* as an immediate outcome variable and *child outcomes* as another broader outcome. The results from this study indicate an immediate outcome variable may exist. Examples of immediate support outcomes may include improvement in knowledge for educational and social welfare rights, improvement in parenting skills, enhancement of family-professional partnerships, and increase in the quality of parent-child interaction. Research should address how the support outcomes correlate with family needs and family quality of life. Furthermore, there has been no explicit evidence verifying the relationship between child outcomes and family quality of life. If a positive relationship is confirmed, this evidence would likely encourage more research and stronger policy related to family support.

Based on the new family quality of life conceptual framework, I recommend three major foci for future research related to family needs and family quality of life. The numbers on Figure 4 correspond with sections outlining ideas for research.

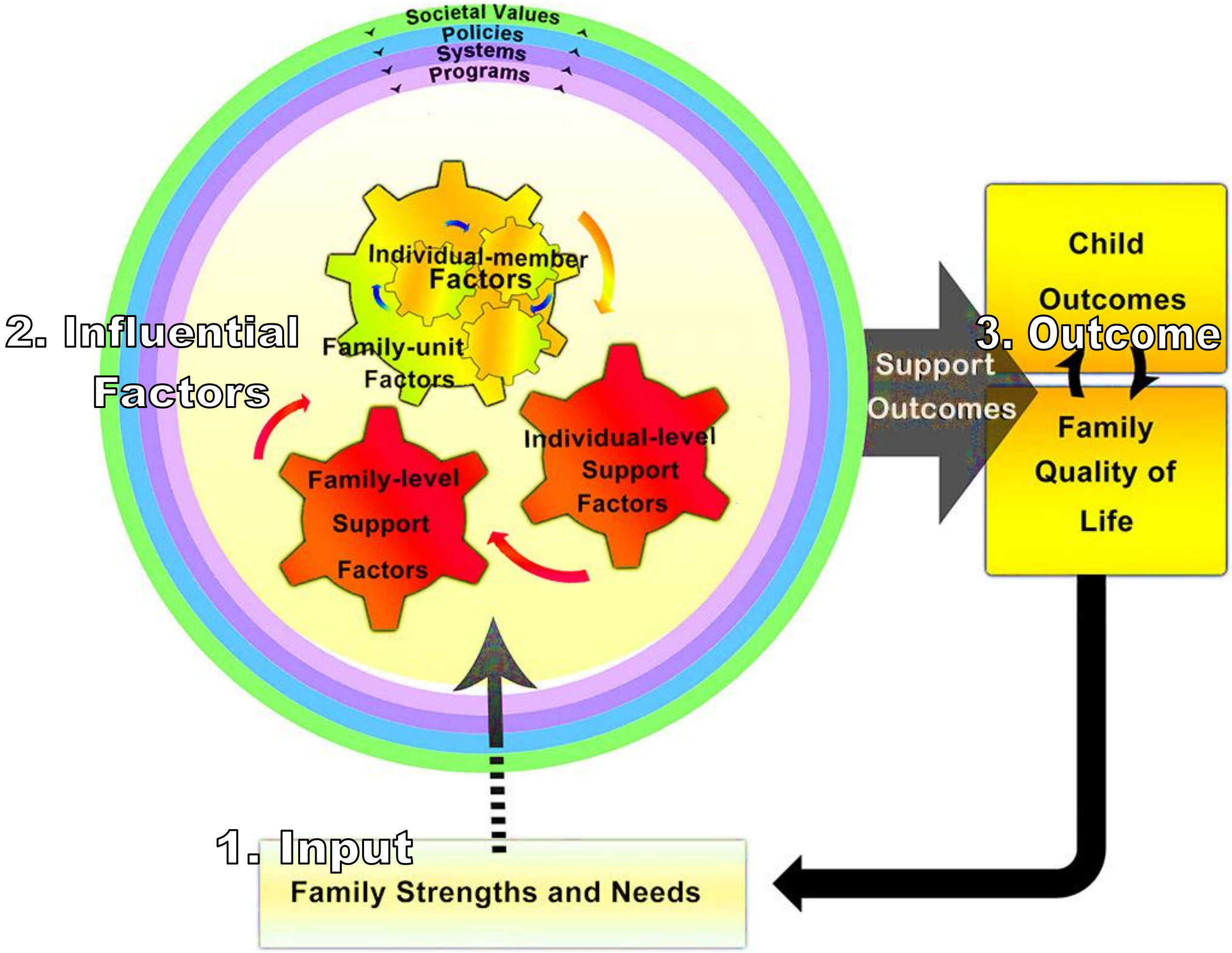

Figure 4. The proposed family quality of life conceptual framework.

1. Input. The FNA study in Chapter 3 concludes that more evidence is needed in supporting the tool’s validity (e.g., a confirmatory factor analysis). In addition to refining quantitative measures when exploring family needs, research should use qualitative techniques to further understand rationale and thinking processes behind the participants’ responses. In addition, since family strengths have the potential to interact with family needs and impact family quality of life, research should operationalize and measure family strengths in families of children with disabilities. What do families consider as “family strengths”? What are the family strengths that are most predicted of positive family positive outcomes? How can professionals and families jointly build on family strengths in addressing family needs? How can the FNA be used in practice?

2. Influential factors. To date, there are more research studies on the individual-member and family-unit factors as compared to systemic and supports factors (Chiu et al., 2013; Kyzar, Turnbull, & Summers, 2012). Thus, in addition to continuing to investigate how family-unit and individual-member factors interact and impact family quality of life, researchers should start focusing on the systemic and support factors. In cross-cultural comparisons across countries, what systemic factors influence the relationship between family needs and family quality of life? In particular, how do traditional values in Asian countries (e.g., strong priority emphasis on academic achievement, collectivism, or filial piety) impact how families perceive family needs and family quality of life? Are the policies adequately addressing family needs and implemented as intended? What types and sources of support are most effective in enhancing family quality of life?

3. Outcome. In addition to examining relationships among the outcomes (i.e., immediate support outcomes, child outcomes, and family quality of life outcomes), research should investigate how the outcomes lead to new family strengths and family needs. How could information about family outcomes be used to identify areas with new needs? Turnbull (2003) proposed feasible ways to use the Beach Center Scale in individualizing family support in light of family strengths and needs; thus, studies are needed to evaluate the effectiveness of her proposal, as well as other options, for using the FNA and Beach Center Scale to develop, monitor, and evaluate individualized family support.

Summary

In this chapter, I provide explanations (i.e., lack of support in a linear correlation between the two constructs and potential measurement issues) for the non-correlation between total/domain mean scores of the FNA and the Beach Center Scale. I further propose changes in the family quality of life conceptual framework and a future research agenda aligned with the framework. This study establishes a foundation for future research in family needs and family quality of life.

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Appendix A: Survey Protocol

(*Note*. The layout was different from the distributed survey because of the differences in written language.)

The Beach Center on Disability, University of Kansas

Family Needs Assessment

Identify. Prioritize. Take Action.

Making a Significant & Sustainable Difference in Quality of Life
Beach Center on Disability

(collaborative association's logo here)

The Family Needs Assessments requires approximately 20-30 minutes to complete. Please return the completed survey before January 4, 2013 with the self-addressed envelopment. To express our appreciation, a 100 N.T. Dollar is enclosed in this package.

We invite you to take part in the first test of a new tool: The We invite you to take part in the first test of a new tool: The Family Needs Assessment. We are an international workgroup of researchers with a strong commitment to quality of life for families who have a member with a disability.

Often, disability-related services focus only on the family member with a disability. We believe that in order to meet the needs of the family member with a disability, services must also meet the needs of the whole family.

The Beach Center on Disability at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty.

Our primary goal is that the Family Needs Assessment will help families and their service providers work together as partners in meeting family needs. Also, we hope that directors of programs can use the Family Needs Assessment to make program decisions. Before we can provide a tool free for you and other families to use, we need to field test this initial version to ensure all items are applicable and precisely measuring the construct of family needs.

Your participation is expected to take approximately 20minutes to complete. The content of the survey should cause no more discomfort than you would experience in your everyday life.

Although participation may not benefit you directly, we believe that the information obtained from this study will help us gain a better understanding of family needs.

Ensuring Your Rights as a Research Participant

- Your participation is solicited, although strictly voluntary. You may withdraw your participation at any time and may choose to skip any questions that you wish.
- All reports of family responses will be used anonymously in any report of this study and provided in group form; no individual responses will be reported.
- Your identifiable information will not be shared unless (a) it is required by law or university policy, or (b) you give written permission.
- Completion of the survey indicates your willingness to take part in this study and that you are at least 18 years old.

We now want to tell you a little bit about the Family Needs Assessment. It is organized into three parts.

Part 1: Identifying Needs

We list some basic tasks that often help families live well together. We will be asking you to rate how much of a need for assistance that one or more of your family members have in being able to do each of the tasks. The options for responding include the range of 1 – "No need" to 5 – "Very high need"

Part 2: Family Quality of Life

We ask you to respond to 21-items on how satisfied you are with regard to your family life.

Part 3: Providing General Child and Family Information

We ask you to provide basic information about you and your child with a disability.

Addressing Questions

If you have any questions about your rights as a research participant, you may call (785) 864-7429, write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, or email irb@ku.edu. If you have any question about the study, please feel free to contact Caya Chiu at chiuc@ku.edu or 0921830312.

Sincerely,

Caya Chiu	Ann Turnbull, Ph.D.
Principal Investigator	Faculty Supervisor
Beach Center on Disability	Beach Center on Disability
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(785) 864-7613	(785) 864-7608
chiuc@ku.edu	turnbull@ku.edu

I am a parent/legal guardian living with an individual with intellectual and developmental disabilities.

☐ **Yes** **No** ☐

Part 1: Identifying Needs

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

One or more family member need…	*1-* *No Need*	*2-* *Low Need*	*3-* *Need*	*4-* *High Need*	*5-* *Very High Need*
1. Monitoring health conditions (having a regular doctor/ health checks)	☐	☐	☐	☐	☐
2. Attending to daily care activities (e.g., bathing, brushing teeth, dressing, eating)	☐	☐	☐	☐	☐
3. Participating in preferred indoor community recreational activities (e.g., movies, concerts, art classes)	☐	☐	☐	☐	☐
4. Helping others (e.g., neighbors, friends) in knowing how to socialize with my family members	☐	☐	☐	☐	☐
5. Feeling supported by professionals at the time of learning about my child(ren)'s disability	☐	☐	☐	☐	☐
6. Participating in goal-setting to enhance family members' learning	☐	☐	☐	☐	☐
7. Having educational services where my child(ren) are making progress	☐	☐	☐	☐	☐
8. Having a clear understanding of each family member's strengths and needs	☐	☐	☐	☐	☐

One or more family member need…	*1-* *No Need*	*2-* *Low Need*	*3-* *Need*	*4-* *High Need*	*5-* *Very High Need*
9. Feeling hope about the future for our family members	☐	☐	☐	☐	☐
10. Having a spiritual community that includes my child(ren)	☐	☐	☐	☐	☐
11. Paying for basic needs (such as food, house, clothing)	☐	☐	☐	☐	☐
12. Coordinating medical care among two or more physicians	☐	☐	☐	☐	☐
13. Going to bathroom	☐	☐	☐	☐	☐
14. Participating in preferred outdoor community recreational activities (e.g., swimming, playing ball, playing in the parks)	☐	☐	☐	☐	☐
15. Helping my family members (e.g., neighbors, friends) in socializing with others	☐	☐	☐	☐	☐
16. Getting new childcare	☐	☐	☐	☐	☐
17. Helping my child(ren) reach goals during every day routines	☐	☐	☐	☐	☐
18. Having appropriate extracurricular / holiday care	☐	☐	☐	☐	☐
19. Talking about feelings, opinions, and challenges with all members in my family	☐	☐	☐	☐	☐
20. Managing stress	☐	☐	☐	☐	☐
21. Teaching my child(ren) about spiritual beliefs	☐	☐	☐	☐	☐
22. Paying school fees and/or child care (baby-sitter)	☐	☐	☐	☐	☐
23. Having appropriate vision and eye care	☐	☐	☐	☐	☐
24. Giving medications	☐	☐	☐	☐	☐
25. Going on family vacations	☐	☐	☐	☐	☐

One or more family member need…	*1-* *No Need*	*2-* *Low Need*	*3-* *Need*	*4-* *High Need*	*5-* *Very High Need*
26. Helping my family members make friends	☐	☐	☐	☐	☐
27. Moving within the same community or to a different community	☐	☐	☐	☐	☐
28. Knowing when my child(ren) is making progress	☐	☐	☐	☐	☐
29. Having access to necessary services, such as speech therapy, physio/physical therapy, orientation and mobility, occupational therapy, audiology, and nursing care	☐	☐	☐	☐	☐
30. Solving problems together	☐	☐	☐	☐	☐
31. Enhancing each family member's self-esteem	☐	☐	☐	☐	☐
32. Understanding my family members' challenges within my family's spiritual beliefs.	☐	☐	☐	☐	☐
33. Paying for special therapies, equipment, or special foods (e.g., adapted switches, behavioral services, gluten-free items) for child with disability	☐	☐	☐	☐	☐
34. Having appropriate care for hearing related needs	☐	☐	☐	☐	☐
35. Getting regular and special resources (such as technology equipment and materials, adapted switches, special foods) needed by family members	☐	☐	☐	☐	☐
36. Doing relaxing things/activities at home	☐	☐	☐	☐	☐
37. Helping all family members to know how to respond to questions about disability	☐	☐	☐	☐	☐
38. Planning for my child(ren)'s successful transition from preschool to primary school or from primary school to secondary school	☐	☐	☐	☐	☐

One or more family member need…	*1-* *No Need*	*2-* *Low Need*	*3-* *Need*	*4-* *High Need*	*5-* *Very High Need*
39. Teaching choice-making and problem-solving	☐	☐	☐	☐	☐
40. Having a trusting partnership with professionals	☐	☐	☐	☐	☐
41. Establishing close emotional bonds among members of the family	☐	☐	☐	☐	☐
42. Having support from other families who have a child with disabilities	☐	☐	☐	☐	☐
43. Saving money for the future	☐	☐	☐	☐	☐
44. Having appropriate dental care	☐	☐	☐	☐	☐
45. Getting childcare	☐	☐	☐	☐	☐
46. Helping all family members know how to responding to negative situations and attitudes (e.g., bullying, teasing, staring)	☐	☐	☐	☐	☐
47. Developing long-term goals for family members	☐	☐	☐	☐	☐
48. Teaching safety in the home and other places	☐	☐	☐	☐	☐
49. Monitoring services to make sure that they are beneficial	☐	☐	☐	☐	☐
50. Being flexible as a family in making changes when they are needed	☐	☐	☐	☐	☐
51. Dealing with challenges related to all family members	☐	☐	☐	☐	☐
52. Getting or keeping a job	☐	☐	☐	☐	☐
53. Getting a full night's sleep	☐	☐	☐	☐	☐
54. Having a break from caretaking (such as respite care)	☐	☐	☐	☐	☐
55. Participating in social occasions with friends, co-workers, or others	☐	☐	☐	☐	☐
56. Starting a new school year	☐	☐	☐	☐	☐

One or more family member need…	*1-* *No Need*	*2-* *Low Need*	*3-* *Need*	*4-* *High Need*	*5-* *Very High Need*
57. Teaching independent living skills (such as eating and dressing)	☐	☐	☐	☐	☐
58. Making changes in services when necessary, even when professionals disagree	☐	☐	☐	☐	☐
59. Providing supports to include all members of my family in family activities	☐	☐	☐	☐	☐
60. Applying for government benefits and addressing government benefit denials	☐	☐	☐	☐	☐
61. Having healthy life style(such as healthy diet/ exercising)	☐	☐	☐	☐	☐
62. Having appropriate transportation	☐	☐	☐	☐	☐
63. Using technological communications (such as email, Facebook) to connect socially with others	☐	☐	☐	☐	☐
64. Planning for the future after I'm no longer able to take care of my family members	☐	☐	☐	☐	☐
65. Teaching child(ren) to attend to toileting needs	☐	☐	☐	☐	☐
66. Knowing and acting on my child(ren)'s educational rights	☐	☐	☐	☐	☐
67. Preventing substance abuse and other addictions (e.g., alchohol, drugs)	☐	☐	☐	☐	☐
68. Ensuring that home and community settings are accessible	☐	☐	☐	☐	☐
69. Teaching social and emotional skills	☐	☐	☐	☐	☐
70. Getting information necessary to make sound decisions about services	☐	☐	☐	☐	☐
71. Feeling supported by professionals to manage the difficulties associated with daily living.	☐	☐	☐	☐	☐
72. Teaching appropriate behavior	☐	☐	☐	☐	☐

One or more family member need…	*1-* *No Need*	*2-* *Low Need*	*3-* *Need*	*4-* *High Need*	*5-* *Very High Need*
73. Feeling informed and helped by teachers about the improvement and the difficulties of my child(ren)	☐	☐	☐	☐	☐
74. Teaching communication skills	☐	☐	☐	☐	☐
75. Teaching motor skills (e.g., riding a bike, walking, climbing stairs)	☐	☐	☐	☐	☐
76. Teaching my child(ren) about sexuality	☐	☐	☐	☐	☐
77. Helping with homework	☐	☐	☐	☐	☐

Part 2: Family Quality of Life

Please think about your family life over the past 12 months. How satisfied you are with these things in your family?:

How Satisfied am I that….	*1-* *Very Dis-satisfied*	*2-* *Dis-satisfied*	*3-* *Neither*	*4-* *Satisfied*	*5-* *Very Satisfied*
1. My family enjoys spending time together	☐	☐	☐	☐	☐
2. My family members help the children to learn to be independent	☐	☐	☐	☐	☐
3. My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
4. My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5. My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
6. My family members have transportation to get to the places they need to be	☐	☐	☐	☐	☐
7. My family members talk openly with each other.	☐	☐	☐	☐	☐
8. My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9. My family members have some time to pursue their own interests.	☐	☐	☐	☐	☐
10. My family solves problems together.	☐	☐	☐	☐	☐
11. My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12. My family members show that they love and care for each other.	☐	☐	☐	☐	☐

How Satisfied am I that….	1- *Very Dis-satisfied*	2- *Dis-satisfied*	3- *Neither*	4- *Satisfied*	5- *Very Satisfied*
13. My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14. Adults in my family teach the children to make good decisions.	☐	☐	☐	☐	☐
15. My family gets medical care when needed.	☐	☐	☐	☐	☐
16. My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17. Adults in my family know other people in the children's lives (i.e. friends, teachers).	☐	☐	☐	☐	☐
18. My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19. Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
20. My family gets dental care when needed.	☐	☐	☐	☐	☐
21. My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐

Part 3: Providing General Child and Family Information

We would like to tell you the reason that we are asking you the questions in this section, because they may seem intrusive to you. We are asking them so that we can identify trends in responses according to specific child and family characteristics.

For example, we might find that the families of children with a particular type of disability tend to have similar needs. We would appreciate your completing this section, but we also want you to feel free to leave out responses if the questions are uncomfortable for you. Again, we will keep this information confidential as described on the first page of the survey.

We want to start with **your information:**

1. **Please check the box next to your relationship to the child in your family who has a disability.**

☐ Parent (biological, step, foster, or adoptive)
☐ Sibling (brother or sister)
☐ Grandparent
☐ Other relatives (please specify):
☐ Other non-relative (please specify):

2. **What is your gender?**

☐ Male ☐ Female

3. **When were you born? Please enter in this format: Please enter in this format: Month (enter a number from 1-12) / Day (enter a number from 1-31) / Year (enter two digits, e.g., 73).**

_

____

MM/DD/YYYY

4. **What is your race/ ethnicity? (check all that apply)**

○ Taiwanese, not aboriginal
○ Taiwanese, aboriginal
○ Chinese
○ Other (Please specify)

5. **What is your marital status?**

☐ Married/ living with a partner
☐ Divorced or separated

☐ Never married
☐ Widowed

6. **What is your employment status?**
☐ Working <u>full-time</u> for pay or profit for a company or family business
☐ Working <u>part-time</u> for pay or profit for a company or family business
☐ Unemployed but looking for work
☐ Not employed (for example, stay-at-home parent or care-giver, retired, public assistance pay, disability)

7. **What is the highest level of education that you have completed? (please check ONLY one)**
☐ Some schooling but not a high school diploma or GED
☐ High school graduate (diploma or GED)
☐ Some college or post-high school, but no degree
☐ Associate degree (AA, AS, etc.)
☐ Bachelor's degree (BA, BS, etc.)
☐ Graduate degree
☐ Other (please specify):

8. **What was your total household monthly income from all sources? Be sure to include income from all sources (such as family subsidy or child support).**
☐ Less than $19,999
☐ Between $20,000 and $39,999
☐ Between $40,000 and $69,999
☐ Between $70,000 and $99,999
☐ Over $100,000

9. **How many people, including you, are supported on this income? ________**

10. **Do you have additional assistance to provide daily support?**
☐ No
☐ Yes, we have help from extended family members (e.g., grandparents)
☐ Yes, we hire a home-based worker

11. **In addition to supporting your child with disabilities, please identify how many other family members require intensive support from you (e.g., another child with disability, elderly).**
☐ 0
☐ 1
☐ 2
☐ 3
☐ More than 3 people

12. **Which city/county do you live in?**

☐ Taipei City
☐ Kaohsiung City
☐ Taichung City
☐ Tainan City
☐ Hsinchu City
☐ Keelung City
☐ New Taipei City
☐ Taoyuan County
☐ Chiayi City
☐ Hsinchu County
☐ Yilan County
☐ Changhua County
☐ Miaoli County
☐ Yunlin County
☐ Nantou County
☐ Taitung County
☐ Penghu County
☐ Pingtung County
☐ Chiayi County
☐ Hualien County
☐ Kinmen County
☐ Lienchiang County

Finally, we want to learn about **your family member with disabilities**:

(If you have multiple family members with disabilities, please think about the one person that requires most support in the following questions)

13. What is the gender of your family member with a disability?

☐ Male ☐ Female

14. **When was your family member with a disability born? Please enter in this format: Month (enter a number from 1-12) / Day (enter a number from 1-31) / Year (enter four digits, e.g., 1975).**

____

MM/DD/YYYY

15. What is the level of severity?

☐ Developmental Delays
☐ Mild Intellectual Disability
☐ Moderate Intellectual Disability
☐ Severe Intellectual Disability
☐ Profound Intellectual Disability

16. **Does your family member with a disability have any ADDITIONAL disability diagnoses other than intellectual disabilities? (Please check ALL that apply)**

○ Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)
○ Autism spectrum disorder
○ Developmental delay or early childhood disability
○ Emotional or behavioral disorder
○ Hearing impairment, including deafness
○ Vision impairment (including blindness)
○ Learning disability
○ Intellectual disability (or mental retardation)
○ Physical disability
○ Speech or language impairment
○ Traumatic brain injury
○ Health impairment (please specify):
○ Other disability (please specify):
○ No specific diagnosis

Do you have any additional information you would like to share about your family which you think may have implications on your family needs?

-Thank you for participating! –

※照片為研究者跟哥哥(極重度多重障礙)小時候的照片

Appendix B: Complete Factor Loading Table (Pattern Matrix)

	Factor									
	1	2	3	4	5	6	7	8	9	10
73.Feeling informed and helped by teachers about the improvement and the difficulties of my child(ren)	.994									
72.Teaching appropriate behavior	.973									
74.Teaching communication skills	.970									
69.Teaching social and emotional skills	.846									
40.Having a trusting partnership with professionals	.805									
66.Knowing and acting on my child(ren)'s educational rights	.755									
76.Teaching my child(ren) about sexuality	.682							.609		
49.Monitoring services to make sure that they are beneficial	.656									
39.Teaching choice-making and problem-solving	.655		.374							
70.Getting information necessary to make sound decisions about services	.615									
17.Helping my child(ren) reach goals during every day routines	.561									
41.Establishing close emotional bonds among members of the family	.556		.454							
71.Feeling supported by professionals to manage the difficulties associated with daily living.	.554									
38.Planning for my child(ren)'s successful transition from preschool to primary school or from primary school to secondary school	.547									
48.Teaching safety in the home and other places	.545									

29.Having access to necessary services, such as speech therapy, physio/physical therapy, orientation and mobility, occupational therapy, audiology, and nursing care	.543					
47.Developing long-term goals for family members	.509					
46.Responding to negative situations and attitudes (e.g., bullying, teasing, staring) to all family members	.505					
64.Planning for the future after I'm no longer able to take care of my family members	.463					
42.Having support from other families who have a child with disabilities	.430					
28.Knowing when my child(ren) is making progress	.380					
50.Being flexible as a family in making changes when they are needed	.372					
20.Managing stress	.346		.338			
12.Coordinating medical care among two or more physicians	.329					
51.Dealing with challenges related to all family members	.314					
44.Having appropriate dental care	.307					.305
13.Going to bathroom		.983				
2.Attending to daily care activities (e.g., bathing, brushing teeth, dressing, eating)		.842				
65.Teaching child(ren) to attend to toileting needs		.832				
35.Getting regular and special resources (such as technology equipment and materials, adapted switches, special foods) needed by family members		.677				
24.Giving medications		.669				

57.Teaching independent living skills (such as eating and dressing)	.395	.571	
75.Teaching motor skills (e.g., riding a bike, walking, climbing stairs)	.352	.549	
34.Having appropriate care for hearing related needs		.536	
68.Ensuring that home and community settings are accessible		.498	
45.Getting child care		.448	
16.Getting new childcare		.446	
54.Having a break from caretaking (such as respite care)		.330	
1.Monitoring health conditions (having a regular doctor/ health checks)		.327	
32.Understanding my family members' challenges within my family's spiritual beliefs.			.744
31.Enhancing each family member's self-esteem			.728
37.Helping all family members to know how to respond to questions about disability			.624
26.Helping my family members make friends			.584
21.Teaching my child(ren) about spiritual beliefs			.569
36.Doing relaxing things/activities at home			.509
30.Solving problems together			.487
15.Helping my family members (e.g., neighbors, friends) in socializing with others			.466
27.Moving within the same community or to a different community	-.326		.462

4.Helping others (e.g., neighbors, friends) in knowing how to socialize with my family members			.455			
10.Having a spiritual community that includes my child(ren)			.452			
19.Talking about feelings, opinions, and challenges with all members in my family	.319		.365			
7.Having educational services where my child(ren) are making progress				.820		
8.Having a clear understanding of each family member's strengths and needs				.796		
9.Feeling hope about the future for our family members				.796		
5.Feeling supported by professionals at the time of learning about my child(ren)'s disability				.657		
6.Participating in goal-setting to enhance family members' learning				.625		
63.Using technological communications (such as email, Facebook) to connect socially with others					.776	
62.Having appropriate transportation					.599	
59.Providing supports to include all members of my family in family activities					.547	
56.Starting a new school year					.536	.393
67.Preventing substance abuse and other addictions (e.g., alchohol, drugs)					.412	
58.Making changes in services when necessary, even when professionals disagree	.363				.376	
61.Having healthy life style(such as healthy diet/ exercising)					.374	.032
11.Paying basic needs (such as food, house, clothing)						.689

22.Paying school fees and/or child care (baby-sitter)						.662		
43.Saving money for the future						.580		
52.Getting or keeping a job					.358	.396		
33.Paying for special therapies or equipment for my child		.306				.396		
60.Applying for government benefits and addressing government benefit denials	.395					.396		
23.Having appropriate vision and eye care								
3.Participating in preferred indoor community recreational activities (e.g., movies, concerts, art classes)							.582	
14.Participating in preferred outdoor community recreational activities (e.g., swimming, playing ball, playing in the parks)							.579	
25.Going on family vacations							.498	
55. Participating in social occasions with friends, co-workers, or others							.398	
18.Having appropriate extracurricular / holiday care							.379	
53. Getting a full night's sleep								
77.Helping with homework	.351				.348			.427

Note. Extraction Method: Principal Axis Factoring. Rotation Method: Promax with Kaiser Normalization. Rotation converged in 17 iterations. Loadings under .30 were not presented in this table.