

RELATIONSHIPS AMONG PERCEIVED WORK-LIFE BALANCE,  
RESOURCES, AND THE WELL-BEING OF WORKING PARENTS

by

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A dissertation submitted to the  
Graduate School-New Brunswick  
Rutgers, The State University of New Jersey

In partial fulfillment of the requirements

For the degree of

Doctor of Philosophy

Graduate Program in Social Work

Written under the direction of

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New Brunswick, New Jersey

January, 2008

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## **ABSTRACT OF THE DISSERTATION**

### **THE RELATIONSHIP BETWEEN WORK-LIFE BALANCE RESOURCES AND THE WELL-BEING OF WORKING PARENTS**

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Dr. Allison Zippay

This two-part study utilizes quantitative and qualitative data to examine how working parents cope with work-life demands. The quantitative component of the study uses a secondary data set from the 2002 National Study of the Changing Workforce (a nationally representative sample of working adults). The research design employs structural equation modeling (SEM) to analyze the associations among the perceptions of workplace support, supervisory support, work-schedule flexibility, work-life balance, and personal well-being. In this study, employee well-being is an endogenous latent construct. Perceived workplace support and perceived supervisory support are latent exogenous constructs. The mediating variables are employees' perceptions of the flexibility of their work schedules and the state of their work-life balance. For the qualitative component of the study, 27 in-depth interviews were conducted in New Jersey with working parents who had a chronically ill or disabled child. The two components of the study contribute to an understanding of the effects of formal and informal workplace supports in enhancing the well-being of employees with children in general and those with a chronically ill or disabled child in particular.

The quantitative study is unique in its examination of work-schedule flexibility and work-life balance as mediating variables and furthers our understanding of which sets of workplace policies and supports are positively associated with employee well-being. Supplementing the quantitative data, the in-depth interviews provide an examination of how and why parents utilize such supports in dealing with the challenging situation of caring for a chronically ill or disabled child. This information will assist social workers in developing more effective intervention efforts in the workplace, with the ultimate goal of increasing employees' quality of life. Specifically, the results of this study will help social workers who work within employee assistance programs to understand how company policies affect employees and how to more effectively intervene to support positive employee well-being and work-life balance. Finally, the findings will inform public policymakers as they continue to develop policies that positively affect employees and their work environment.

## **Acknowledgements**

I would like to acknowledge many people for helping me during my doctoral work. I would especially like to thank my advisor, Dr. Allison Zippay, for the crucial guidance she provided me with throughout the dissertation process. I feel privileged to have had her as my chairperson. I want to thank her for her encouragement and helpful feedback. Furthermore, she has provided me with many outstanding learning opportunities. She consistently stimulated me to think critically and assisted me in developing my dissertation in all of its stages. I am deeply grateful for her insight on issues that challenged me to improve my work.

I would like to express my gratitude to the members of my outstanding committees. I am very grateful for having an exceptional doctoral committee, especially for their guidance, patience, support, and encouragement.

Dr. Eleanor Brilliant provided insight into how to build my complex study right from the proposal-writing phase. I was fortunate in having her as my committee member before she retired. I would like to give my special thanks to her for being willing to participate in my doctoral committee. I would especially like to acknowledge the valuable guidance, ideas, suggestions, and support she provided me with for the past several years. She provided a great deal of insight into how to strengthen my project.

Dr. Chien-Chung Huang encouraged me to work more thoroughly with the quantitative data. I especially appreciated his help with the quantitative sections. I

want to thank him for his willingness to read and re-read these sections. I am very grateful for the assistance and advice with which he provided me.

Dr. Eileen Appelbaum provided me with important resources. In particular, my qualitative project would not have been possible without the benefit of her assistance and support. Specifically, she was awarded the Rutgers University 2005 President's Research in Service to New Jersey Award to examine family leave and work-life balance with parents of children with chronic conditions, and I thank her for offering me the opportunity to participate in this research for my dissertation. Additionally, I would like to thank her for the generosity, support, and ideas with which she provided me over the past several years.

I would like to thank Karen White for excellent research assistance and Jaime Maddalena for assistance with the interviews. I am thankful for the constant support from my mother, sisters, brothers, and all of my friends.

Finally, I also appreciate that the respondents were willing to share their experiences. It was a privilege to participate in the interviews with the respondents, and I learned a great deal from them in the process.

## Table of Contents

ABSTRACT OF THE DISSERTATION .....	ii
Acknowledgements.....	iv
Table of Contents.....	vi
List of Tables .....	viii
List of Figures.....	ix
CHAPTER 1: INTRODUCTION.....	1
Statement of the Problem.....	2
Conceptualization: Work-life balance .....	14
Purpose and Goals of Study.....	15
Importance of the Study.....	17
The Study’s Importance for Social Work .....	22
CHAPTER 2: LITERATURE REVIEW.....	25
Border Theory.....	25
Family Stress Theory .....	29
Historical Background and Research on Workplace Policies .....	34
Recent Research on Workplace Support, Supervisory Support, Work-Schedule Flexibility, Work-Life Balance, and Employee Well-Being.....	36
Parents with a Chronically Ill Child or a Child with a Disability.....	43
Summary.....	52
CHAPTER 3: METHODOLOGY.....	53
Research Design.....	53

<i>Part I: Secondary Analysis</i> .....	53
<i>Part II: In-depth Interviews</i> .....	63
CHAPTER 4: RESULTS .....	72
Part I-Quantitative Study .....	72
Part II-Qualitative Study .....	89
CHAPTER 5: DISCUSSION.....	118
The NSCW Data .....	118
Theoretical Implications .....	133
Recommendations for Further Research.....	136
Recommendations for Social Work Practice .....	138
Recommendations for Policymakers .....	142
Limitations .....	145
Conclusion .....	147
APPENDICES .....	150
Appendix A: Measures Used in This Study.....	150
Appendix B : Questionnaire 1.....	153
Appendix C : Interview Questionnaire .....	167
Appendix D: Introduction to Individual Interviews.....	174
Appendix E: Individual Informed Consent.....	176
BIBLIOGRAPHY .....	179
C.V.....	191

## List of Tables

Table 1: International parental leave policies .....	5
Table 2: Federal leave policies in the United States .....	6
Table 3: State leave policies in the United States .....	8
Table 4: Percentage of companies offering paid maternity and paternity leave (fathers and adaptive parents) .....	13
Table 5: Categorization of specific disabling conditions.....	44
Table 6: Survey respondents' demographic information.....	55
Table 7: Survey respondents' demographic information.....	66
Table 8: Selected characteristics of respondents' children .....	67
Table 9: Respondents' knowledge of leave policy and leave experience.....	69
Table 10: Means, standard deviations, and correlations for the variables.....	73
Table 11: Goodness of fit indices for the confirmatory factor structures .....	75
Table 12: Confirmatory factor analysis .....	77
Table 13: Goodness of fit indices for the confirmatory factor structures .....	79
Table 14: Factor correlation.....	79
Table 15: The mediation effects .....	85
Table 16: Indices for goodness of fit .....	87
Table 17: Direct effects of Construct Variables .....	88

## List of Figures

Figure 1: Conceptual model of workplace support, supervisory support, work-schedule flexibility, work-life balance, and employee well-being .....	50
Figure 2: Confirmatory factor analysis .....	76
Figure 3: The partially mediated model between workplace policies and the well-being of working parents (Model A) .....	82
Figure 4: The partially mediated model between work-schedule flexibility and the well-being of working parents (Model C) .....	83
Figure 5: The fully mediated model between workplace policies and the well-being of working parents (Model B).....	84
Figure 6: The fully mediated model between work-schedule flexibility and the well-being of working parents (Model D) .....	85
Figure 7: SEM model.....	86

## CHAPTER 1: INTRODUCTION

Working parents whose children are under 18 years old tend to have more demanding family responsibilities than employees with adult children or without children (Bond, Galinsky, Kim, & Brownfield, 2005; Wyn, Ojeda, Ranji, & Salganicoff, 2003). Accordingly, the availability of family support policies is particularly important for employees with younger children because they have both childcare responsibilities and work demands. The present research is composed of two studies, both with the purpose of exploring the effects of formal and informal employer-based policies to support parents' work-life balance. This research will provide important information to help develop effective interventions for working parents to increase employee well-being.

Quantitative and qualitative methods were utilized to gather data about the strategies used by working parents to balance work and family obligations. Specifically, a quantitative data set from the 2002 National Study of the Changing Workforce ( $N = 1,200$ ) was used to analyze the associations among perceived workplace support, perceived supervisory support, work-schedule flexibility, and working parents' work-life balance, and well-being. The qualitative component consisted of 27 in-depth interviews with employees who had a child with a chronic illness or disability. Both studies investigated the types of resources that positively influenced work-life balance and employee well-being. In particular, the quantitative study sought to answer the question, "How are workplace policies related to parents' work-life balance and well-being in general?" The qualitative study examined the

question, “How do working parents cope with the difficulties of having a child who is chronically ill or disabled?”

### Statement of the Problem

Working parents often have difficulties in attempting to balance employment responsibilities with family and childcare responsibilities (Families and Work Institute [FWI], 2004b; FWI, 2004c; Galinsky & Johnson, 1998). These challenges are greater among working parents who have a child with a chronic illness or disability. In turn, work-life conflicts have been found to be associated with mental health issues including stress and depression (Emslie, Hunt, & Macintyre, 2004; Rosenfield, 1989). The quantitative study examined how workplace policies are related to work-life balance and employee well-being in general, and considered the association among working parents’ perceptions of workplace support, supervisory support, and parental well-being while examining mediators of these relationships. The qualitative study explored parents’ experiences when they faced the situation of having a chronically ill or disabled child.

Currently, 63% of U.S. adults over age 16 are employed (U.S. Department of Labor, 2007). According to the U.S. Department of Labor Women’s Bureau (2007), women comprise 46% of the total U.S. labor force. An examination of 25 years of U.S. workforce trend data by the Families and Work Institute revealed that 78% of employees were living in dual-earner families in 2002, up from 66% in 1977. Furthermore, about 43% of these dual-earner workers had children under age 18, and among these families, those headed by women were more than twice as likely to be living in poverty as those headed by men (22% versus 10%) (Families and Work Institute, 2005a). It has been found that mothers in this situation find it difficult to

balance work demands and childcare responsibilities and are more likely than their childless counterparts to leave the workforce involuntarily (Barnett, 2004; Cobble, 2004; Hochschild, 1989). Other working parents may benefit from the availability of “family-friendly policies” such as on-site childcare, work-schedule flexibility, supervisory support, maternity leave, and paternity leave (Berg, Kalleberg, & Appelbaum, 2003; Estes, 2004; Ezra & Deckman, 1996; Galinsky & Johnson, 1998; Guest, 2002; Keene & Quadagno, 2004; Marquart, 1991; Salzstein, Ting, & Salzstein, 2001; Tracey, 1999). The benefits of “family-friendly policies,” however, are limited to a minority of workers (Barnett, Del Campo, Del Campo, & Steiner, 2003; Evans, 2002; Lambert, 1993; Salzstein et al., 2001) because the availability of such benefits varies widely among employers (Ruhm, 1997a, 1997b; Waldfogel, 1996, 1998, 2001a, 2001b).

Historically, the US has relied primarily on individual companies to set family policies for their employees. Unlike other industrialized countries, the US had no national family and medical leave legislation prior to 1993, when the Family Medical Leave Act (FMLA) was signed into law. The FMLA provides many employees with up to 12 weeks of unpaid leave in the event that they experience a serious health problem of their own, need to bond with a new child (e.g., because of a birth, adoption, or new foster child), or need to care for a parent, spouse, or minor or disabled child with a serious health problem. This leave is “job protected,” which means that the employer is required to hold the employee’s job during the leave period or offer the employee a similar job upon his or her return. The FMLA provides job-protected family leave to about half of U.S. employees (Waldfogel, 1996). The eligibility guidelines are described in the provisions of the act as follows:

To be eligible for FMLA leave, an individual must (1) be employed by a covered employer and work at a worksite within 75 miles of which that employer employs at least 50 people; (2) have worked at least 12 months for the employer; and (3) have worked at least 1,250 hours during the 12 months immediately before the date of the FMLA leave begins. (Pub. L. No. 103-3, 1993)

Workers in companies with fewer than 50 employees in a 75-mile radius, who are new to the workforce, and who are returning to paid employment are not eligible for this leave. Moreover, the leave is unpaid, so many people either cannot afford to take leave or ultimately decide to shorten their leave. In other words, although the FMLA is widely seen as a positive policy for families in pursuit of work-life balance, the unpaid nature of the leave represents a primary obstacle to families wishing to take advantage of its benefits (Dorman, 2001; Ruhm, 1997a, 1997b; Waldfogel, 1996, 1998, 2001a, 2001b).

Table 1 (Waldfogel, 2001b) shows childbirth-related leave policies in the US and 10 peer nations. Leave in the US is relatively short in comparison to maternity leave to birth or surrogate mothers and parental leave to the biological or adoptive parents for a newborn or an adopted child in other nations (Gornick & Meyers, 2004). Additionally, the unpaid leave policy in the US differs from the paid leave policies offered in most other countries. In fact, every industrialized country in the world, except the US, has some form of paid parental leave with a guaranteed job upon return to work (Waldfogel, 2001b). For example, among 158 countries around the world, 130 have leave policies for mothers and fathers, with 98% of those policies offering paid leave. Only three countries that have leave policies, the US, Ethiopia, and Australia, only have an unpaid leave policy (FMLA Survey and Information, n.d.).

Table 1  
International Parental Leave Policies

Country	Type of leave provided	Months	Payment rate
United States	12 weeks of family leave	2.8	Unpaid
Canada	17 weeks maternity leave 10 weeks parental leave	6.2	15 weeks at 55% of prior earnings 55% of prior earnings
Denmark	28 weeks maternity leave 1 year parental leave	18.5	60% of prior earnings 90% of unemployment benefit rate
Finland	18 weeks maternity leave 26 weeks parental leave Childrearing leave until child is 3	36.0	70% of prior earnings 70% of prior earnings Flat rate
Norway	52 weeks parental leave 2 years childrearing leave	36.0	80% of prior earnings Flat rate
Sweden	18 months parental leave	18.0	12 months at 80% of prior earnings, 3 months flat rate, 3 months unpaid
Austria	16 weeks maternity leave 2 years parental leave	27.7	100% of prior earnings 18 months of unemployment benefit rate, 6 months unpaid
France	16 weeks maternity leave parental leave until child is 3	36.0	100% of prior earnings Unpaid for one child; paid at flat rate (income-tested) for two or more
Germany	14 weeks maternity leave 3 years parental leave	39.2	100% of prior earnings Flat rate (income-tested) for 2 years, Unpaid for third year
Italy	5 months maternity leave 6 months parental leave	11.0	80% of prior earnings 30% of prior earnings
United Kingdom	18 weeks maternity leave 13 weeks parental leave	7.2	90% for 6 weeks and flat rate for 12 weeks, if sufficient work history; otherwise, flat rate Unpaid

*Note.* From “International Policies toward Parental Leave and Child Care,” by J. Waldfogel. (2001b, p.103), *The Future of Children*, 3, 99-111. Copyright 2000 by Princeton University and The Bookings Institution; Kamerman, S. B. From maternity to parental leave policies: Women’s policies: Women’s health, employment, and child and family well-being. *The Journal of the American Women’s Medical Association* (Spring 2000) 55: Table 1; Kamerman, S. B. Parental leave policies: An essential ingredient in early childhood education and care policies. *Social Policy Report* (2000) 14: Table 1.0.

Many employees in the US are not covered by the FMLA. According to Waldfogel (2001a), only about 46.9% of private-sector employees were both eligible for and covered by FMLA leave in 2000, a figure almost identical to that from 1995 (46.5%). Some employees are able to receive partial wage replacement through other sources such as unemployment insurance or temporary disability benefits when they take family leave. Only 53% of employers provide at least some replacement pay during periods of maternity leave, with most (81%) providing assistance through Temporary Disability Insurances (TDI) (Waldfogel, 2001a). Table 2 details the current federal leave policy in the US, and Table 3 presents the policies of states that have their own leave legislation.

Table 2  
Federal Leave Policy in the United States

	Federal FMLA elements
Employer covered	-Private employers of 50 or more employees in at least 20 weeks -public agencies -local education agencies
Employees eligible	-worked for employer for at least 12 months -worked at least 1,250 hours -employed at employer worksite with 50 or more employees
Leave amount	Up to a total of 12 weeks during a 12-month period
Type of leave	Unpaid leave
Serious health condition	Illness, injury, impairment, or physical or mental condition involving incapacity or treatment connected with inpatient care in hospital, hospice, or residential medical care facility; or, continuing treatment by a health care provider involving a period of incapacity
Health care provider	Doctors of medicine; podiatrists, dentists, clinical psychologists, clinical workers, optometrists, chiropractors, nurse practitioners, and nurse-midwives; Christian Science practitioners; any provider; and any health provider

Federal FMLA elements	
Intermittent leave	Permitted for a serious health condition
Substitution of paid leave	Employees may elect or employers may require accrued paid leave to be substituted in some cases
Reinstatement rights	Must be restored to same position or one equivalent to it with all benefits
Key employee exception	Limited exception for salaried employees if among highest paid 10% of company's employees, within 75 miles of worksites
Maintenance of health benefits during leave	Same conditions as prior to leave
Leave requests	To be made by employee at least 30 days prior to date of leave
Medical certification may be required by employer for:	Request for leave because of a serious health condition

*Note.* From Employment Standards Administration. Federal vs. state family and medical leave laws. Washington, DC: Department of Labor; National Partnership for Women & Families (n.d.). Highlights of the state round-up.

Table 3  
State Leave Policies in the United States

State FMLA	State TDI	Paid sick leave
<p>The following 11 states and the District of Columbia have implemented legislation similar to the Federal Family and Medical Leave Act (FMLA): California, Connecticut, Hawaii, Minnesota, New Jersey, Oregon, Rhode Island, Vermont, Washington, and Wisconsin. The District of Columbia covers employees. Maine, Minnesota, and Oregon cover firms smaller than the federal FMLA guidelines of 50 employees or more.</p> <p>Only California allows employees to take partially paid family leave (a policy that began after July 1, 2004). This paid family leave program will allow workers to take up to six weeks off to care for a newborn, a newly adopted child, or an ill family member. Under this new law, employees have been eligible to receive 55% of their wages during their absence, up to a maximum of \$728.00 per week. Also, all employers are covered by the California Family Rights Act.</p> <p>Washington State's 2007 Family Leave Insurance Law will provide \$250 per week for up to five weeks to a full-time worker to care for a newborn or newly adopted child beginning October</p>	<p>The following 5 states have TDI systems or require employers to offer TDI, which provides partial wage replacement to employees who are temporarily disabled for medical reasons, including pregnancy-or birth-related medical reasons: New York, California, New Jersey, Rhode Island, and Hawaii. TDI is funded by employee or employer contributions or both and ranges in coverage from 26 to 52 weeks.</p>	<p>San Francisco began to offer Paid Sick Leave as of February 6, 2007. The specific regulations are as follows: (a) All employers must provide paid sick leave to each employee including temporary and part-time employees who work in San Francisco; (b) paid sick leave shall begin to accrue 90 days after the commencement of employment; (c) for every 30 hours worked, an employee shall accrue one hour of paid sick leave; and (c) employees are entitled to paid sick leave for their own medical care and also to aid or care for a family member or designated person</p>

*Note.* From Employment Standards Administration. Federal vs. state family and medical leave laws. Washington, DC: Department of Labor; National Partnership for Women & Families (n.d.). Highlights of the state round-up.

As shown in Table 3, New Jersey has its own leave legislation, including the New Jersey Family Leave Act (NJFLA), which was passed in 1992, and TDI, which the state has had in place since the 1940s. TDI provides up to 26 weeks of paid leave for New Jersey residents in covered employment for maternity leave for doctor certified health conditions. In the case of maternity leave, the current rate for 2007 for new mothers is two-thirds of their pay up to a maximum of \$502 a week. Maternity leave in New Jersey typically begins 2 weeks before the baby is expected and continues for 6 to 8 weeks after child birth depending on the difficulty of the delivery. NJFLA provides up to 12 weeks of job-protected, unpaid leave in a 24-month period to employees at firms with more than 50 employees when necessary to care for a seriously ill family member or to bond with a new child. A woman in covered employment who has just given birth will typically have 8 weeks of maternity leave during which she draws partial wage replacement through TDI. At the end of this period, payments from the TDI fund stop, but the woman still has 4 weeks of unpaid FMLA leave she can use. Typically, if she takes bonding leave after that, the employer will run the clock on the last 4 weeks of FMLA leave and the first 4 weeks of NJFLA leave simultaneously against her entitlement under both laws. The new mother will then have 8 weeks of NJFLA leave remaining. She can choose to use this immediately for bonding with the new baby, in which case she would have a total of 20 weeks of combined FMLA and NJFLA job-protected maternity and family leave available to recover from childbirth and to bond with the new child. Alternatively, she can “save” part of her NJFLA leave to be used later, if necessary, as family leave. For parents who need to take time off from work to care for a child with a chronic condition, the FMLA and NJFLA clocks will typically run simultaneously. However, if the child has two different medical conditions that require care, the parent can use

up unpaid FMLA for the first condition and will still be able to use unpaid NJFLA for the second health condition. Many employees have access to medical leave for their own serious health conditions through the state's TDI program because paid leave is provided by the state for a certain period in the event that a NJ resident has to leave his or her job to deal with a serious personal health condition.

Working parents who do not have access to paid leave have an increased risk for and incidence of stress as they attempt to manage their role responsibilities (Thoits, 1991). Moreover, because women continue to carry the bulk of childcare and home responsibilities, working mothers with children tend to experience greater role stress (Thoits, 1991). Among working parents with children under age 18, mothers generally have more difficulties with work-life balance than fathers because mothers still tend to have the primary responsibility for children and household chores (Barnett, 2004; Barnett & Hyde, 2001; Gerson, 2002). In addition, there are other family responsibilities such as budgeting, caring for aging parents, and shopping that may fall more heavily on women. Finally, the challenges of work-life balance are especially difficult for single and low-income women with children.

Many low-income workers cannot take advantage of the FMLA because they cannot afford to take unpaid leave (Cobble, 2004; Phillips, 2004; Waldfogel, 2001a). McDowell, Ray, Perrons, Fagan, and Ward (2005) claim that the family-friendly policies are not beneficial for many women in lower paying positions for financial reasons. For instance, many women that work for small firms are likely to be excluded from benefits, a further result of job segregation and a cause of the gender wage-gap (Evans, 2002). In addition, some women still face involuntary leave because of childbirth (Cobble, 2004), and others may choose to work part time because they believe it helps to make balancing work and family easier even though

part-time work is less likely to offer the benefits, higher wages, and security of full-time work (Evans, 2002). As a result, lower-class women or single mothers often have greater difficulties in taking advantage of unpaid leave policies because they are more likely to work in a lower wage or part-time positions (Barnett et al., 2003; Employment Policy Foundation, 2005).

Work-life balance is also particularly challenging for parents of children with a chronic physical illness or disability. In a 2001 national survey of children with special health care needs by the U.S. Department of Health and Human Services (2004), it was found that one in five families with children in the US had a child with special health care needs (U.S. Department of Health and Human Services, 2004), and most of those families had one or both parents in the workplace; additionally, parents of children with special health care needs such as impairment indicators, chronic illnesses, and cognitive, emotional, or school-related problems were less likely to be employed as full-time workers. In addition, using the 1994 National Health Interview Survey ( $N = 21,415$ ), which included 1604 children with special needs, Heck & Makuc (2000) found that 90% of children with special needs living with single parents were with their mothers. For such families, the US provides only unpaid leave for serious illnesses through the FMLA. According to Heymann, Earle, and Hayes (2007), at least 145 nations provide publicly paid leave for short- or long-term illnesses, with 127 nations providing a week or more of publicly paid sick days annually. According to the Families and Work Institute (2004b), it is estimated that 8.6% of employees in the US may have a child with special needs.

In the 2005 National Study of Employers by the Families and Work Institute, surveys were conducted with 1,092 employers from a diverse sample of organizations, including for-profit and non-profit companies, to examine the practices,

policies, and benefits provided by U.S. employers to respond to employees' needs (Families and Work Institute, 2005b). According to this survey, 31% of employers allowed some employees to use flextime. Five percent of employers offered programs for parents of young children and teenagers such as on- or near-site childcare, childcare resources and referral services, dependent care assistance plans, and so forth. Only 5% of the parents of teens received Employee Assistance Program (EAP) services, which are "services offered by employers to their employees to help them overcome problems that may negatively affect job satisfaction or productivity. EAP services may be provided on site or contracted through outside providers and include counseling for alcohol dependence and drug dependence, marital therapy or family therapy, career counseling, and referrals for dependent care services." (Barker, 1995, p. 119). Thirty-four percent of employers provided elder care resources to employees. Comparing the benefits offered by company size, large employers (1,000 or more employees) were more likely than small employees (50-99 employees) to provide on- or near-site childcare (17% vs. 5%) and EAPs (76% vs. 36%). Also, 63% of all employers reported that supervisors were encouraged to be supportive of employees' needs in balancing their work and family responsibilities; however, only a small number of employees reported that the organization was actually supportive in this regard (Bond et al., 2005). Additionally, in case studies of New Jersey employers, Appelbaum and Milkman (2005) found that few employers provided paid family leave. Most working parents of special needs children rely on taking sick days, vacation days, or unpaid absences to care for their children.

As described above, the primary leave policies for working parents in covered employment in the US are the unpaid FMLA, paid TDI in the five states that have it, and the varied and idiosyncratic work policies of individual companies. With respect

to company leave policies, many companies offer vacation days, holidays, personal days, and sick leave. Nearly half of workers do not have paid sick leave. In particular low-wage workers have very little access to adequate paid sick leave benefits (Lovell, 2004). Table 4 shows the statistics for the maternity and paternity leave offered by the 100 companies selected by the Institute for Women’s Policy Research’s review of the Working Mother 2006 100 Best Companies.

Table 4  
Percentage of Companies Offering Paid Maternity and Paternity Leave (Fathers and Adaptive Parents)

Number of weeks of leave	Maternity (%)	Paternity (%)	Adoptive (%)
More than 12 weeks	8	0	1
11 to 12 weeks	11	0	3
9 to 10 weeks	9	0	0
7 to 8 weeks	20	0	3
5 to 6 weeks	28	7	9
3 to 4 weeks	10	8	13
1-2 weeks	7	35	17
0 weeks <sup>a</sup>	7	50	46

*Note.* Institute for Women’s Policy Research. (2007). Maternity leave in the United States.

According to the Institute for Women’s Policy Research (2007), even among the best U.S. employers, only a small number of companies offer paid maternity leave and paternity leave. In general, the amount of paid time off and vacation depends on the length of service. As a result, strategies to achieve work-life balance often depend on personal solutions, and many working parents are vulnerable to and at risk of losing income or a job when their child faces a crisis or chronic illness.

*Conceptualization: Work-life balance*

In the present research, work-life balance is a mediating variable among the study's major conceptual components. Guest (2002) defines balance as, "satisfaction and good functioning at work and at home with a minimum of role conflict." Several researchers define "work/life balance" as a three dimensional time and space measure involving personal time, family care, and work (Ungerson & Yeandle , 2005; Williams, 2001). However, some scholars have refused to use the concept work-life balance because they believe that the term is based on "gender blind" perspectives that disregard power differentials and cultural barriers that women face in organizations (Smithson & Stokoe, 2005). Caproni (2004) criticized the term because it includes an individualistic, achievement-oriented ideology based on modern concepts of organization. Thus, Caproni asked a fundamental question about who defines work-life balance within a post-modern perspective. Even though there are some debates regarding the term "balance," many scholars have pointed out that a focus has been shifted from work-family balance to work-life balance (Lambert & Haley-Lock, 2004) or from role conflict and work-family/home conflict to work-life balance (Emslie et al., 2004).

For this study, work-life balance is conceptualized as "a perception of good functioning at work and at home with a minimum of perceived role conflict" (Guest, 2002). We used three indicator questions from the NSCW data set to measure work-life balance: (a) "How much do your job and your family life interfere with each other?"; (b) "How easy or difficult is it for you to manage the demands of your work

and your personal or family life?"; and (c) "How often have you not had enough time for your family or other important people in your life because of your job?"

### Purpose and Goals of Study

This research is comprised of two related studies using two data sets and employs both quantitative and qualitative methods. The quantitative study is concerned with how working parents with children under 18 manage work-life conflicts. The qualitative study explores the experiences working parents who have a chronically ill or disabled child. The common purpose of both the quantitative and qualitative studies is to investigate the factors that help make working parents' work-life balance possible and to identify various strategies that can help to improve their well-being. The overall aim of the two studies is the same because both are interested in parents' coping strategies to deal with work-life conflicts. However, the two studies are different in terms of populations, methods, and research questions that correspond with the unique goals of each study. Thus, the present research seeks to provide a comprehensive understanding of work-life conflicts and strategies to deal with them.

The quantitative study focuses on the effects of certain workplace policies on working parents in general. The quantitative study uses data from the 2002 National Study of the Changing Workforce (NSCW), a large, nationally representative data set of employed adults in the US. This study first examines the relationships between perceived workplace support, perceived supervisory support, work-schedule flexibility, work-life balance, and employee well-being with employees who have children under 18 years old. The three benefits (i.e., workplace support, supervisory support, and work-schedule flexibility) can be provided at little cost to employers, so

it is important to examine their effects in that many employees, in principle, can access them more easily than other more costly workplace policies (FWI, 2004b). The present studies use Clark's (2000) border theory and the boundary-spanning resources model (Voydanoff, 2004) as theoretical foundations. In addition, the framework draws upon Barnett's (2002) arguments about mediating influences of work-life balance.

The qualitative study pays attention to the experiences of parents in challenging family situations. Specifically, the qualitative study reports the findings from 27 in-depth interviews that took place in New Jersey with parents of chronically ill or disabled children. The interviews examine these parents' coping strategies and the ways in which various family policies affect these strategies and parents' perceptions of work-life balance. The qualitative interviews illuminate the situations that these parents face and explore the ways in which they have adjusted their lives to cope with work and family demands. The specific aim of the qualitative study is to reveal how boundary-spanning resources affect parents' work-life balance and well-being. The theoretical foundation for the qualitative component is family stress theory (Patterson, 2002).

Quantitative measures provide generalizable results on the associations of perceived workplace support, perceived supervisory support, work-schedule flexibility, work-life balance, and employee well-being, whereas the qualitative analysis provides a unique, in-depth exploration of the work-life balance issues of parents with chronically ill or disabled children. Together, these studies build an empirical base that has implications for policy and intervention alternatives and the potential roles for employers, social workers, and others involved with working parents and workplace issues.

### Importance of the Study

Today, almost all working parents have multiple roles through the domains of work and home, and many working parents experience work-life conflict in their daily lives (FWI, 2004b; FWI, 2004c; Galinsky & Johnson, 1998). Some previous studies have found associations between work-life conflicts and mental health issues including stress and depression (Emslie et al., 2004; Rosenfield, 1989). Relationships between work-life balance and mental health outcomes such as stress or depression are supported by a conflict model, which means if there are high levels of demand in all spheres of life, then there may also be more difficult life choices. Work-life conflicts often increase parents' stress for reasons such as limited time- and work-related pressures or make parents feel depressed because of the burdens of work-family responsibilities (Guest, 2002). Unlike the conflict model, Barnett and Hyde (2001) claim that multiple roles with an appropriate balance are beneficial for dual-earner couples; this claim is based on an expansionist theory, which is "an inductive theory of gender, work and family that includes empirically derived and testable basic principles that are better suited to today's realities" (p. 784). According to Barnett and Hyde, if employees accomplished multiple roles and work-life balance by effective use of supportive workplace policies, they would benefit from lower levels of stress or depression.

Many researchers have analyzed work-to-family or family-to-work influences through spillover theories, which focus on influences on employees' emotional states both at work and at home (Keene & Reynolds, 2005; Mennino, Rubin, & Brayfield, 2005). These studies have attempted to identify positive and negative emotional outcomes in the work and home environments and the causal factors leading to them

in order to support the development of effective workplace policies for employees and employers. Regarding specific workplace policies, some researchers have studied the effects of formal policies such as maternity leave, paternity leave, work-schedule flexibility, and on-site childcare on workers' work-life balance (Evans, 2002; Ezra & Deckman, 1996; Marquart, 1991; Salzstein et al., 2001). Other researchers have examined the effects of informal workplace supports such as supportive culture and supervisory support (Secret & Sprang, 2001).

Despite numerous studies that have examined the associations between formal or informal policies and work-life balance and employee well-being, a comprehensive, empirically validated model of that association has yet to be developed. The model for the quantitative component of the present study was developed to address unresolved relationships and to expand the existing literature. Even though the potential benefits of work-related coping resources have been discussed in previous work, there are very few studies that have examined the relationship of the overall associations of workplace policies, work-life balance, and the well-being of working parents. Compared to other multivariate statistical techniques, Structural Equation Modeling (SEM) is better equipped to identify relationships among existing workplace policies and mediation effects, and thus may result in implications for new and alternative interventions.

This study provides a unique analysis of working parents' perceptions of the supports offered by employer-based family policies. Several researchers have pointed out that the availability of family support policies enhance employee-perceived control and symbolize corporate concern regardless of whether an employee uses the policies (Clark, 2002; Grover & Crooker, 1995). Many employees may hesitate to use some policies such as flextime if the policies are not formally established or when

they are made to feel uncomfortable about using them (Warren & Johnson, 1995).

When employees feel that they are able to access the workplace policies without any penalty, they are likely to have more positive perceptions of the company's policies and supportiveness of work-family balance. Thus, it is important to find ways to "enhance workers' perceived control over managing the work-family boundary and legitimize the use of work-family policies" (Voydanoff, 2004, p. 401).

Regarding the methodology of the quantitative component, very few studies exist on supportive work policies and employee well-being that have used SEM (Feldt, Kinnunen, & Mauno, 2000; Halpern, 2005; Thompson & Prottas, 2006). Previous studies have generally used a large number of multiple regression analyses and the corresponding beta values as path coefficients to examine the ways that work policies affect employee work-life balance and/or well-being rather than to look at the overall relationships between the variables. A few studies have examined mediating effects. For instance, Halpern (2005a) applied SEM to analyze the relationships among stress, health, and job commitment among employees with access to time-flexible work policies with the 1997 NSCW. In his analyses, the relationships of five constructs were examined: need for time-flexible policies, number of time-flexible policies, work-related stress, commitment to employer, and cost to organization. Halpern found that time-flexible policies directly affected the employee's commitment to employer- and work-related stress; specifically, employees with time-flexible work policies reported less stress and a higher level of commitment. However, Halpern's study only focused on the relationships between time-flexible policies and stress and did not consider other mediating variables such as work-life balance. Using SEM on the 2002 NSCW data set, Thompson and Prottas (2005) tested a confirmatory factor analysis model that included relationships between

various forms of formal and informal support, attitudes, and well-being. Specifically, they examined relationships among the availability of formal organizational family support, job characteristics (job autonomy), informal organizational support, perceived control, and employee attitudes and well-being. They found that perceived control mediated the relationships between formal and informal support, job autonomy, and employee attitudes and well-being. Thompson and Prottas' study is important in that job autonomy mediated the relationship between informal support and employee outcomes. The degree to which employees perceive overall control in the workplace is often reflected in the degree or level of work-life balance; however, the abovementioned studies did not consider the level of work-life balance. Unlike Thompson and Prottas' study, the present quantitative study examines the mediating effects of informal support (workplace support and supervisory support) on employee well-being. Feldt et al. (2000) conducted a longitudinal study to examine the relationship between job insecurity and well-being in central Finland. In the first stage, the participants consisted of 636 employees among four organizations, and after one year, in the second stage, there were 518 employees. Using LSREL to conduct their SEM analyses, they found that a good organizational climate and high job security were linked to general well-being as well as to coping-linked personality characteristics such as self-confidence.

The use of the exogenous constructs (workplace support and supervisory support) in the present study is supported by prior research that has looked into the major factors affecting employee well-being and health. Based on these previous findings, the present study will make a contribution to the field by examining a related but rarely studied issue through testing a mediator model. The strengths of the study are that it investigates intervening factors in relationships between informal

supportive policies and employee well-being and will contribute to the further development of effective practices to enhance the latter.

With respect to the second study, there are few qualitative studies that have looked at the work and life experiences of parents who live with the challenging situation of having a chronically ill or disabled child. Research has neglected the effects of workplace policies on employees in such circumstances, so there is little information on employees' diverse needs and coping strategies. One limitation of close-ended instruments in a large data set, as in the present quantitative study, is that they do not allow the employees to describe in depth the concerns and coping strategies that apply to dealing with having a child with a chronic condition. A few researchers have examined the experiences of parents who have children with a disability using in-depth interviews (Heymann, Toomey, & Furstenberg, 1999; Kerr & McIntosh, 1999). For example, Gjengedal, Rustoen, Wahl, and Hancstad (2003) explored parents' experiences with caring for children that have cystic fibrosis and found that parents had a desire to create a "normal" life for themselves. Kerr and McIntosh (2000) found that parents of children with special needs had more positive parent-to-parent support. This and other similar studies have mostly focused on parents' care experiences and the strategies they use to cope with challenging family circumstances. There are very few studies that have examined the coping strategies that working parents utilize in both the family and work spheres.

One study (Heymann et al., 1999) emphasized the benefits of the availability of time-off for working parents with a child with a disability. However, even though some previous studies have examined the coping strategies of parents that have children with chronic conditions, they have not considered parents' struggles with work-life balance and how they use resources to manage their work demands and

responsibilities for a child with a chronic condition. The present study afforded parents the opportunity to tell how they have coped with the demands of balancing work and a family with special needs. No other study has used in-depth interviews with parents to capture their views of the ways in which such support can help or hinder the management of work and family responsibilities.

### The Study's Importance for Social Work

A primary function of the social work profession is to enhance individual and family well-being, particularly among families that are facing difficult or extraordinary circumstances. The challenges of balancing work and family can negatively affect many aspects of family life including mental health, child well-being, and income generation. Increasingly, eligibility for welfare includes a work requirement, and greater numbers of welfare recipients and other poor and low-income recipients of assistance are managing work and family obligations. Thus, a better understanding of the effects of employer-based policies and public policies such as the FMLA can provide social workers with empirical evidence to shape advocacy and interventions regarding family-friendly employment policies and to assist clients with identifying or negotiating work settings that may optimally advance work-life balance and well-being.

The philosophy for this study is grounded in three notions: (a) the right to a positive well-being for all people in the workforce (Gil, 1992), (b) "equality and social justice in the distribution of work-life 'opportunities'" (Lambert & Haley-Lock, 2004), and (c) the support that resources offer in expanding an individual's options to manage life responsibilities (Sen, 1987). The philosophy points to the importance of

work and family policies in increasing employees' choices to manage work demands and family responsibilities. For example, working people need time to be able to care for themselves and others, including their dependents, and flexible work schedules can help offer parents this time. However, resources that help parents to manage work-life balance, such as work-schedule flexibility, are very limited. Even though most people agree that work and family are central life concerns, there has been little attention in the field of social work to ways to increase happiness through integrating work demands and family life. In particular, there are few studies about work-life balance by social work scholars based on a social welfare perspective (Bargal, 2000; Iversen, 1998; Secret & Sprang, 2001).

Social work scholars have studied the effectiveness of various practical interventions to promote family well-being and quality of life and advance mental health by reducing stress and depression (Institute for the Advancement of Social Work Research, 2003). However, there are relatively few studies that address or integrate issues related to work-life conflict. The findings of this study have implications for improving current public policy such as the FMLA and individual companies' policies. The quantitative study utilized a model whose findings could potentially help create a useful work-life intervention program. Also, both the quantitative and qualitative studies have implications for comprehensive practical interventions for working families or individuals who receive public assistance that requires work for continued eligibility. In addition, this study can be used for the design and delivery of individual counseling and organizational policies within a work setting, EAPs including employee-supervisor relationship development, casework focused on a variety of work-family related challenges with clients who

have a low income or children with disabilities, and advocacy for family-friendly workplace policies.

## CHAPTER 2: LITERATURE REVIEW

This chapter presents the theories that provide the main conceptual framework for the study. Border theory (Clark, 2001) and the concept of boundary-spanning resources (Voydanoff, 2004) make up the foundation for the quantitative study, and family stress theory (Patterson, 2002) provides the foundation for the qualitative study. First, the historical background of research on workplace policies is discussed. Then the literature review for the quantitative study examines the relationships among workplace support, supervisory support, work-schedule flexibility, work-life balance, and employee well-being. Finally, for the qualitative study, previous studies of parents with a chronically ill child or a child with a disability are reviewed.

### Border Theory

Border theory posits that work and family are separate but mutually influential domains. According to this theory, individuals negotiate between the work and family spheres in order to attain work-life balance. The central proposition of border theory is that “integrating work and family facilitates transitions between these domains” (Desrochers & Sargent, 2004, p. 41).

Since the rise of industrialism, the workplace has become increasingly separated from the family, and the concept that work and family are respectively regarded as public and private spheres has intensified (Parsons & Bales, 1955). Such a dichotomous view of these social spheres presumes that a nuclear family serves an

ideal family function with the workplace being a public place for men and the home being a private and appropriate place for women. Parsons & Bales describe the two spheres as being hierarchical, with a high value on paid labor in the market and a low value on caring labor in the household. Thus, the dichotomy of public and private places can be seen as problematic in that it intensifies gender inequality. While dual-earner families have increased during the past few decades, many working families face problems in managing the care of their dependents while dealing with work demands in the overlapping spheres of work and family. Bonney (2005) found that the separation of the workplace and the home intensifies the long hours, gender division, and social ignorance of caring work. Lambert (1993) pointed out that the existing job structures no longer fit for married or single working parents.

In previous research on work-life balance, studies were mainly based on spillover theory, which focuses on emotional influences from home to work and work to home (Keene & Reynolds, 2005; Mennino et al., 2005). Using NSCW data, these studies examined factors that were related to reductions in conflicts and negative spillover of the separate domains of work and home. The major findings were that workplace policies such as work-schedule flexibility reduced negative spillover, especially for women. The spillover model has made contributions in identifying the factors that influence employees' work-related emotions at home or home-related emotions at work. However, this model is based in the assumption that work and family are two separate dimensions and supports traditional ideas about the roles of men and women in work and family spheres.

In contrast, Clark's (2000) more recent border theory is based on the concept that "people are daily border-crossers." This theory emphasizes the possibility and reality that people can easily move between home and work (Guest, 2002). Border

theory focuses on integrating work demands and family life with a minimum of role conflict to cut across the two domains. The outcome of interest in border theory is work-family balance, which refers to “satisfaction and good functioning at work and at home, with a minimum of role conflict at work” (Clark, 2001, p. 751). As an effective route to attain work-life balance, Clark (2000) emphasizes the availability of flexible workplace policies that support employee’s autonomy. Clark has dissected the concept of “family friendly” to distinguish between practices associated with temporal flexibility, which gives workers some autonomy of when they work, and operational flexibility, which allows for autonomy of the content of work and supportive supervision and also allows for rules to be flexible in the case of a family crisis, illness, and so forth. With respect to outcomes of people’s daily lives based on the concept of the border theory, some scholars have expressed concern about women’s double burden due to the blurring of the boundary between work and the family (Jacobs & Gerson, 2004; Runte & Mills, 2004).

Voydanoff (2004) examined how work demands and resources were related to work-to-family conflict and facilitation. She found that time- and strain-based work demands were positively related to work-to-family conflict, and that boundary-spanning resources were positively related to the facilitation of work and family responsibilities. She used the concept “boundary-spanning resources” as the interface between the work and family domains. In order to examine the relationships with work-family conflict or facilitation, she included parental leave, family time off, organizational support of work-family balance, and supervisory support of work-family balance as boundary-spanning resources. Using the 1997 NSCW subsample of 2,012 wage and salary workers, Voydanoff (2004, p. 401) reported that, “boundary-spanning resources may reduce work-family conflict and increase work-family

facilitation through interrelated processes that enhance workers' perceived control over managing the work-family boundary." Based on Voydanoff's approach, the quantitative component of the present study predicts that boundary-spanning resources such as workplace support, supervisory support, and a flexible work schedules may facilitate work-family balance with less conflict between work demands and family responsibilities. Also, the quantitative study examines the relationships among workplace support, supervisory support, and work-schedule flexibility.

Many spillover researchers have also examined the emotional influences that work has on employees' home lives and vice versa and have identified important determinants of these influences. However, spillover theory has limitations in that it is based on the existing work-society structure and the corresponding assumptions that a "good and normal" employee must spend long hours at work and consider her or his work a priority. Compared to spillover theorists, border theorists assume that working people should spend their time at work and at home somewhat equally, and therefore they argue that "people are daily border-crossers." As a result, employees do not have to try to fit themselves into rigid conceptions of work and family structures. Instead, they may decide how to make or utilize these structures to attain work-life balance with a desired level of flexibility.

The present quantitative study also draws on Barnett's (2002) hypotheses about the mediating influences of work-life balance. Specifically, Barnett explained work-life conflict and balance as mediating influences in the relationships between workplace circumstances and employee outcomes. The present study applies her insights about the indirect effects of work-family conflict and balance as mediators in the relationships between job conditions and quality of life. In particular, in place of

Barnett's variables of job conditions and quality of life, the present quantitative study examines the perceived availability of workplace policies as related to employee well-being. In the theoretical model (see Figure 1), work-family conflict mediates the relationships between workplace situations and quality of life. The quantitative study explores work-life balance as a mediating variable that may affect working parents' well being.

### Family Stress Theory

Family stress theory argues that when a family faces a stressor, it may produce a crisis, especially if the family's new stressor is not able to be taken care of by the family's existing resources. Thus, family stress theorists point out that the resources available at the personal, family, and community levels are positively associated with the family's ability to deal with crisis situations. Generally, family theorists focus on ways to manage family demands and strategies to adapt to a crisis. In particular, the qualitative component of this study applies the family adjustment and adaptation response model (FAAR). The propositions of the FAAR model (Patterson, 1988, 2002) are as follows: (a) A new stressor occurs because of a pileup of demands; (b) resources are related to potentially strong family capabilities; (c) coping behaviors may affect the adaptation to these capabilities. Patterson also considered demands, capabilities, and meanings as major constructs and emphasized the importance of collaborative attitudes and relationships at the individual, family, and community levels in dealing with a chronic illness. Family stress theory provides the theoretical foundation for the present qualitative study, which examines how parents with a chronically ill or disabled child solve the problems involved with coping with work demands and caring for their child.

Family stress theory has received a great deal of attention in the literature (Boss, 1988; Hill, 1958; McCubbin & McCubbin, 1993; McCubbin, McCubbin, Thompson, & Thompson, 1995; McCubbin & Patterson, 1983; Patterson, 1988; Patterson, 2002). Hill (1958), the first family stress theorist, proposed to address the family stress process. Specifically, Hill's longitudinal study made use of the prolonged absence of fathers in the Vietnam War to examine the changes over time of family stressors. A later stress theory, called the Double ABCX model, emphasized the processes and factors that are used to manage family demands and to adapt to stressful events. These early theories included two major propositions: (a) unexpected events are usually perceived as a stressor, and (b) events such as a serious illness within the family are defined as stressful, especially for families that have not experienced stressful events previously. Based on this theory, an event such as a chronic illness or disability within the family can be defined as a stressful event. Additionally, whether the stress is temporary or not depends on existing family resources, perceptions of the event, and adaptive resources.

A further expansion of the early family stress theories can be found in the FAAR model (McCubbin & McCubbin, 1991; Patterson, 1988; Patterson, 2002), which focuses on families' adjustment and adaptation to stressful life events. This theory addresses the process of family adjustment and adaptation rather than simply examining the family process that follows a stressor. Family adjustment and adaptation include all resources at the personal, family, and community levels. For example, the pileup of family demands by an event such as a serious family illness is theorized to be negatively related to family adaptation. On the other hand, the strengths of the family system, the family's resources, the family's positive appraisal of the situation, and coping strategies based on positive relationships between family

members are theorized to be positively related to family adaptation (McCubbin, 1993).

The FAAR model is particularly appropriate for our qualitative study of parents who have a child with a chronic condition. There are several empirical studies that have examined the impact of chronic childhood illnesses and parental coping behaviors on family stress that utilize the FAAR model (Patterson, 1985; Patterson & McCubbin, 1983). For example, Patterson & McCubbin (1983) examined 100 parents of chronically ill children, and Patterson (1985) studied 72 parents of a child with cystic fibrosis; both studies emphasized family resources and coping strategies and empirically supported the FAAR model. According to Patterson (1988), when a child is diagnosed with a chronic illness, this can be a new stressor for a family. While the new stressor interacts with existing strains, the new demand on the family generates chronic strains as well as increasing any ongoing family strains. At the same time, Patterson (1988) emphasizes that families are not static, but can change over time. For example, if a child is diagnosed with a chronic illness, it may cause a crisis in a family; however, in the process of adaptation, if the demands and resources are balanced, the crisis may be temporary. For example, this may occur when parents have adequate resources such as finances available for medical care and caregivers for their diagnosed child. In addition Patterson (1988, 1991, 2002) emphasizes active efforts to balance family demands with family capabilities in the process of family adjustment and adaptation, thus integrating the family stress theory and the family resilience perspective that is based on the FAAR model.

Patterson (2002, p.351) also pointed out that, “the process of adapting to major, non-normative stressors, such as the diagnosis of a child’s chronic health condition, often involves changing prior beliefs and values as a way to make sense of

the unexplainable and as a way to adapt.” If the imbalance created by such an event in a family persists, the family will experience a period of significant disorganization and instability (McCubbin & Patterson, 1983; Patterson, 2002). Thus, the family’s capabilities (i.e., resources and coping behaviors) are emphasized in the FAAR model. Resources include all those resources available at the personal, family, and community levels, and the coping behaviors are actions intended to achieve a balance between demands and resources (Patterson, 1988). It is important for family members to find various resources to help them cope because stressors and resources, including informal and formal social supports, are related to achieving a positive quality of life (Patterson, 2002). Using family stress theory as a foundation, the present qualitative study examines how parents with a chronically ill child or a child with a disability mobilize resources to cope with both their caring and work responsibilities.

However, family stress theories, including the resiliency model of family stress, adjustment, and adaptation, focus primarily on family demands and on achieving a balance in family functioning while considering mediating factors such as personal, family, and community resources. Such family adjustments and adaptations are closely related to parents’ work demands, but workplace issues have rarely been considered in family stress theories. Of course, McCubbin and Patterson (1983) do mention that when parents have to invest in work-for-pay, the family needs to reestablish a balance between family and work demands (e.g., sharing the housekeeping responsibilities, limiting the amount of time spent at work, using day care, etc.). Nevertheless, these authors defined the family as a semi-closed system, with the implication being that the family and work domains are somehow separate and based on a traditional family structure with defined roles for the father and the mother. In addition, the usefulness of family stress frameworks is likely to be limited

to adaptations in a crisis situation for two-parent families because this framework essentially assumes a traditional nuclear family in which men work in the labor market and women stay at home. For example, one of the discourses about adaptation focuses on the role changes of wives in response to stressful situations, such as, for example, the loss of the family's father. However, family structure varies by household type. For instance, there are many single families and dual-earner families in modern society. In 2004, 51% of civilian households were headed by married dual earners, only 21% were headed by married single earners, and single mothers and single fathers made up 22% and 6% of families, respectively (Employment Policy Foundation, 2005). Thus, this theory could benefit from modifications in order to be applicable to various families' circumstances and structures, such as crisis situations within single-parent and dual-earner families.

Another point made by family stress theorists is that stress is incurred when role demands exceed their abilities. As an example, McCubbin and Patterson (1983, p. 18) explained that "the stressor of a wife-mother entering or returning to work may precipitate an imbalance if the family demands she make a priority commitment to family life and the children." However, existing theories have rarely focused on tension revolving around the family's gender roles. The qualitative component of this study contributes to family stress theory by focusing explicitly on the workplace experiences of families facing the stressor of raising a child with a chronic condition or disability. It also addresses how work and family life are shaped through the family processes of family stress, adjustment, and adaptation in response to this challenging situation.

## Historical Background and Research on Workplace Policies

Workplace policies such as workplace support, supervisory support, and work-schedule flexibility and their respective relationships to the changes in family structure and the workforce have been studied since the 1960s. The employment rate of mothers with children under age 18 grew from 47% in 1975 to 71% in 2005 (U.S. Department of Labor, 2006). Accordingly, there have been working women, employers, and feminists that have demanded changes to help working women manage their family life while maintaining their job. Employers have tried to find methods that enable employees to function in the workplace with minimal interruptions in family care responsibilities. Feminist scholars have pointed out that most women continue to have the primary responsibility for children and household chores, arguing that many women have the double responsibilities of the home and the workplace and that their work as caretakers is still undervalued (Barnett, 2004; Barnett & Hyde, 2001; Chodorow, 1978; Gilligan, 1982; Hochschild, 1989).

Many previous studies on the effects of workplace policies have focused on formal policies, often classified as “family-friendly policies,” such as maternity leave, paternity leave, work-schedule flexibility, and on-site childcare, rather than informal policies such as a supportive workplace culture and supervisory support (Evans, 2002; Ezra & Deckman, 1996; Marquart, 1991; Salzstein et al., 2001). There have been some inconsistent findings on the effects of formal policies such as on-site childcare (Berg, Kalleberg, & Appelbaum, 2003). Using the 1991 Survey of Federal Employees (SOFE) (Ezra & Deckman, 1996; Salzstein et al., 2001) some studies have identified that the use of resources such as on-site childcare increase perceived work-family balance (Ezra & Deckman, 1996; Salzstein et al., 2001) and job satisfaction (Salzstein et al., 2001). The positive findings on family-friendly policies from these studies have

served as catalysts to initiate visible policies such as workplace childcare centers in individual companies.

However, some researchers have expressed concerns about formal policies such as leave provisions, flexible scheduling, and childcare support because they see them as likely to be adopted by employers to maximize productivity while in fact having a negative impact on women's work-family balance (Jacobs & Gerson, 2004; Runte & Mills, 2004). Bruegel and Gray (2005, p. 148) pointed out that family-friendly policies may hinder "fathers' involvement with their children's care, even if such formal policies like family-friendly employment are generally constructed as a means of reducing the stress on mothers in employment." Mennino et al. (2005), who examined wage and salaried workers ( $N = 2,877$ ) using the 1997 NSCW, found that the availability of company policies such as dependent care benefits and flextime was less effective in reducing negative spillover than improvements in the atmosphere of the workplace. Similarly, Berg, Kalleberge, and Appelbaum (2003) found that such formal policies were less effective than employee participation and workplace atmosphere in increasing employees' perceptions that the company helped them balance their work and family responsibilities. In short, Berg et al. argued that formal policies offer visible benefits for employees, but involve dilemmas that can maintain gender gaps or reproduce employers' benefits without changing the fundamental work environment.

On the other hand, many other researchers have found consistently positive effects of informal workplace policies such as supervisory support and workplace support on employees' well-being and outcomes (Behson, 2005; Neal & Hammer, 2006; Secret & Sprang, 2001). For instance, using the 1997 NSCW data, Behson (2005) examined dual-earner families who had a child under 18 or provided care for

someone over 65. The findings revealed that managerial support was more beneficial to work-family balance than the availability of benefits in the workplace.

Furthermore, a study by Secret and Sprang (2001) that interviewed 374 employed parents who had children under age 18 found that dynamic components such as supervisory support rather than structural components such as formal policies were more likely to affect work-family stress; this study's framework was based on a spillover model that was anchored in the concept, "one world can influence the other in either a positive or a negative way" (Guest, 2002, p. 258). Both of the abovementioned studies are important in that they examined the effects of formal and informal workplace policies. The expectation of positive findings for informal workplace policies are incorporated into the conceptual model for the quantitative component of this study.

#### Recent Research on Workplace Support, Supervisory Support, Work-Schedule Flexibility, Work-Life Balance, and Employee Well-Being

This section reviews the recent research on "boundary-spanning resources" such as workplace support, supervisory support, and work-schedule flexibility, which are hypothesized to be related to the work-life balance and well-being of working parents in the quantitative component of this study. Among these variables, the importance of informal policies such as workplace support or supervisory support has been documented in previous studies. Even though some studies have found weaker effects for formal policies, the importance of work-schedule flexibility has been greatly debated in the literature, particularly because there is lack of empirical information about the association between work-schedule flexibility and other workplace variables. Some previous studies have found certain facets of job

flexibility, such as flexible work hours, to be positively associated with some aspects of family life (Ezra & Deckman, 1996), to decrease absenteeism and turnover (Dalton & Mesch, 1990; Galinsky & Johnson, 1998; Milkman & Appelbaum, 2004), and to increase job satisfaction (Hill, Hawkins, Ferris, & Weitzman, 2001; Salzstein et al., 2001; Scandura & Lankau, 1997). Moreover, Hill et al. found positive associations between perceived job flexibility and work-life balance. Additionally, Jacobs and Gerson (2004), in their book, *The Time Divide*, drew upon nationally representative data (the 1992 and 1997 waves of the NSCW) to describe life in the US as divided into various dimensions such as work and family life, parenting, and gender. While Jacobs and Gerson focused on explaining overall trends in the work and family lives of U.S. workers, they pointed out that flexibility at work is a major strategy for reducing work-family conflict.

On the other hand, research has also indicated that flexible work hours are negatively related to long work hours and the traditional gender division of household labor (Wharton, 1994). Specifically, Wharton conducted in-depth interviews with 30 women in 17 real estate firms using a snowball sampling method to examine how they managed paid and unpaid household work. Wharton's case study found that flexible scheduling had the potential for integrating work and family demands, but it seemed to maintain "the second shift" (Hochschild, 1989), in which women performed the bulk of unpaid work such as the housework and childcare after completing a shift of paid work. Even though studies have found inconsistent results on workplace flexibility, many studies have found positive effects of work-family balance using variables such as schedule flexibility or perceived job flexibility in multiple regression analyses (Estes, 2004; Ezra & Deckman, 1996; Hill et al., 2001; Salzstein et al., 2001). The present quantitative study builds on this research by examining the

effects of flexibility using a multidimensional construct, *work-schedule flexibility*, which is measured by three indicator questions: (a) “How much control do you have in scheduling your work hours?”; (b) “Is this schedule perfect for you, okay but could be better, not very good, or not at all what you want?”; and (c) “How hard is it for you to take time off during your work day to take care of personal or family matters: very hard, somewhat hard, not too hard, or not at all hard?” The quantitative component of the present study uses flexibility as a mediator between informal workplace policies and work-life balance in order to address unsolved discrepancies in the employee outcomes and flexibility literature and to identify the associations between informal workplace policies (workplace support and supervisory support) and work-schedule flexibility.

In terms of work-life balance, researchers have also noted that the adoption of a supportive workplace culture in companies may be an important variable (Appelbaum, Bailey, Berg, and Kalleberg, 2005). For instance, Appelbaum et al. (2005, p. 68) pointed out that “workplace climate and supervisors’ attitudes continue to be a key factor in regulating employee access to formal policies.” A supportive culture means that an organization’s overall structure is sensitive to employees’ family needs without prioritizing work over family issues. A supportive workplace culture may be related to the existence of formal flexible scheduling policies in a workplace, such as flexible daily start and finish times for shifts. Warren and Johnson (1995) conducted a study with 116 working mothers in Canada to investigate the effects of family-friendly policies and gender differences. The findings revealed that a supportive organizational culture, which included a supportive work environment and the availability of family-oriented benefits, was associated with lower levels of work-family strain. However, in this study, the respondents participated as volunteers, so

the results may have been different if other workers with a low degree of interest in the study had participated. The NSCW data used for the present study are based on a randomly selected sample, so the potential bias found in non-probability sampling is avoided. Mennino et al.'s (2005) study using the 1997 NSCW used the same variables as the present quantitative study to measure workplace support. Their findings indicated that supportive workplace cultures reduced negative spillover, and that emotional feelings or mood in the workplace influenced others including their family members. Thus, in the quantitative component of the present study, it is expected that workplace support will be positively related to work-life balance.

In addition, many researchers have pointed out that supervisors' support in organizations is very important for balancing work-life demands (Behson, 2005; Mennino et al., 2005; Secret & Sprang, 2001). In particular, supportive supervision allows for rules to be flexible in the case of a family crisis or illness (Clark, 2000). Mennino et al.'s (2005) study also used the same variables as the present quantitative study to measure supervisory support. Based on their positive results, it is expected that supervisory support will also be positively related to work-life balance in the present study. Secret and Sprang (2001) conducted a study with a sub-sample of 374 employed parents that was representative of employees at small and medium companies. The findings revealed positive effects of informal supervisory support on work-family balance. The authors pointed out that studies using SEM are necessary because they can strengthen the construct validity of the findings.

In the present quantitative study, construct validity is examined via SEM with latent variables including perceived workplace support, perceived supervisory support, work-schedule flexibility, work-life balance, and employee well-being. SEM offers a more rigorous method to address potential mediating relations than multiple

regression analysis. This analysis will provide knowledge about the process by which these variables influence the well-being of working parents. Thus, this quantitative study examines the effects of mediating variables between informal supportive resources and employees' well being.

Four control variables are used in the quantitative component of this study: gender, marital status, income, and job status. This section examines the research that applies to the relationships in the conceptual model of the quantitative study. First, many previous studies have examined the proposition that gender differences are predictors of work and home/family conflict (Emslie et al., 2004; Higgins, Duxbury, & Lee, 1994; Keene & Quadagno, 2004; MacDonald, Phipps, and Lethbridge, 2005; Milkie & Peltola, 1999; Rosenfield, 1989). Rosenfield found that women were more likely than men to have mental health problems related to having multiple roles. Regarding the effects of such conflict, Emslie et al. (2004) found that work-home conflict was associated with mental health problems. MacDonald, et al. (2005) found that women experienced more stress about childcare issues. In a study using the 1998 Canada General Social Survey (GSS) (MacDonald et al., 2005), the authors examined gender differences in employee well-being. The total sample included 3,304 women and 2,947 men. Using multivariate analyses, the authors found that women experienced more stress than men because they spent a greater number of hours doing unpaid household work. Indeed, most previous studies have found that women experience more conflict between their roles as an employee at work and as a mother at home than men (for a review see Guest, 2002). Accordingly, the quantitative component of this study uses gender as a control variable to investigate the differences in employee well-being while examining the relationship between work-life balance and well-being.

Several previous studies have examined work-life conflict, gender, marital status, and mental health. For example, Rosenfield (1989) examined the employment and mental health issues of married individuals using three different data sets, including the Fifty Communities Study ( $N = 554$ ), the Americans View Their Mental Health Restudy (1,356), and a study of individuals in southern California ( $N = 229$ ) using probability sampling methods. Emslie et al. (2004) conducted a study with 2,176 full-time, white-collar employees of a British bank using a mail survey. Both Emslie et al. and Rosenfield found that work-home conflict was associated with mental health problems and that married women had higher levels of anxious and depressive symptoms than married men. Using the 1996 General Social Survey (GSS) data, Milkie & Peltola's (1999) study consisted of 209 women and 260 men. They found that women's work-life imbalance was related to marital dissatisfaction and burdens at home while men's imbalance was associated with longer work hours. In a study using the 1996 GSS ( $N = 444$ ) and the 1996 NSCW ( $N = 479$ ), Keene & Quadagno (2004) also found gender differences between married workers with respect to their perceived work-family balance. While women reported that they felt more balance when they had support from the family, men reported that they felt more balance when they had enough personal time. These studies are important in terms of trying to capture women's and men's different perceptions about the balance or imbalance between work and family roles. In short, the perceptions of work-schedule flexibility might differ by gender and marital status. It is important to note that over 80% of the respondents in the GSS and NSCW data were White, and their studies may not be representative to other ethnic groups.

Barnett et al. (2003) pointed out that the majority of studies on work-family balance are biased because they were based on middle-class samples. In their own

research, they examined 400 Mexican-Americans who worked as university employees. They found that single mothers had more difficulties in balancing work and family responsibilities. Also, low income employees had more difficulties in balancing work and family responsibilities because they did not have access to leave with income replacement. As a result, in the present study it is expected that relatively low-income working parents (based on yearly household income) may have a lower level of well-being than high-income working parents. Low-income workers have more care giving responsibilities than their higher-income counterparts (Bond et al., 2005; Heymann, Boynton-Jarrett, Carter, Bond, & Galinsky, 2002). According to Reynolds's study (2005), when working individuals face work-life conflict, those with higher incomes are more likely to want to reduce their work hours. It was speculated that low-income workers would be less likely to reduce their hours because they cannot afford to lose earnings. Moreover, using NSCW data, several researchers found that low-wage and low-income working parents were less likely to take advantage of care benefits than higher earning parents (Bond et al., 2005; Heymann et al., 2002). Thus, in the present study it is expect that low-wage and low-income working parents will have more work-life conflict and stress than high-wage and high-income working parents.

Job status is also an important factor regarding work-life balance. Many employees, especially women, choose to work part time because they believe that it is likely to make it easier to balance work-family demands, even though part-time work tends to be less well-paid and less secure than full-time work (Evans, 2002). Additionally, certain part-time schedules, such as weekend shifts, make it easier for mothers to take care of their young children during weekdays (Garey, 1999). In particular, Guest (2002, p. 266) pointed out that the work context, such as demands of

work, affect perceptions of work-life balance “that can be defined subjectively or objectively.” For example, full-time employees have more work demands than part-time workers, so they are likely to face more work-life conflict (Chung, Garfield, Elliott, Carey, Eriksson, & Schuster, 2007). Thus, in the present analyses it is expected that job status will affect work-life balance.

### Parents with a Chronically Ill Child or a Child with a Disability

Balancing work and family is particularly challenging for parents who have a chronically ill or disabled child, yet very little information is available about the ways in which formal and informal family policies assist families in such situations. Today, most parents hold jobs, 43% of employees have children under 18, and 70% of children have a working mother (Appelbaum & Milkman, 2006; FWI, 2004b). Approximately 20% of all households with children have a child with a chronic condition (FWI, 2004c), which is defined by the U.S. National center for Health Statistics as a condition that lasts three months or more. The FMLA is intended to enable employees to take time off from work to care for seriously ill family members without any risk of losing their job. A survey conducted in 2000 of employees nationwide found that workers who did not have access to leave took less time off than workers with such access, and workers who only had unpaid leave available took less time off than those with the access to paid leave (Waldfogel, 2001a). As previous studies have found, a lack of access to paid time off exacerbates the worker’s difficulties in balancing work and family life.

Of the estimated 13% of children with a chronic condition in the US, asthma and cystic fibrosis are the most common chronic diseases (Mansour, Lanphear, & DeWitt, 2000). The prevalence of asthma in the US in children under 18 years of age

is nine million, or 12% of all children (DHHS, 2006), and approximately 1,000 children are born with cystic fibrosis every year (Cunningham & Taussig, 2003; Cystic Fibrosis Foundation, 2007). Other common chronic conditions include congenital heart disease, transverse myelitis, multiple handicaps, Down syndrome, attention deficit hyperactivity disorder (ADHD), mental retardation, cancer, and autism. According to the U.S. National Center for Health Statistics (2005), 6.9% of children with a chronic health condition have limitation of activity. Table 5 shows various categorizations of specific disabling conditions.

Table 5  
Categorization of Specific Disabling Conditions

DEVELOPMENTAL DISABILITIES		
PHYSICAL	COGNITIVE	EMOTIONAL
Cerebral palsy	Mental retardation	Emotional disturbance
Spina bifida	Autism	
Birth defect	Traumatic brain injury	
Major orthopedic impairment (e.g., absence of limb, osteogenesis imperfecta, etc.)	Severe learning disabilities	

CHRONIC HEALTH CONDITIONS		
DEGENERATIVE	EPISODIC	CONSTANT
AIDS	Leukemia	Technology dependent
Cystic fibrosis	Cancer	(ventilator, apnea monitor, gastronomic tube, etc.)
Muscular dystrophy	Hemophilia	Dialysis
Tuberous sclerosis	Seizure disorder	Diabetes
Neurofibromatosis	Sickle cell anemia	
Heart disease	Severe asthma	

*Note.* From "Being a family; the experience of raising a child with a disability or chronic illness," by J. Knoll, 1992, *Monographs of the American Association on Mental Retardation*, 18, p. 9-56. Copyright 2000 by the American Association on Mental Retardation.

If a child has one of the conditions described in Table 4, it is likely that her or his parents will have more difficulties managing work and life responsibilities than parents with a child without such a condition. The present qualitative study includes New Jersey parents with a child having any of the conditions described above. According to the FWI (2004b), the majority of parents who have children with these conditions work for pay, and so work-life balance is a salient issue. Nevertheless, in national surveys conducted in 2002, only 2% of all employees took family leave to care for a seriously ill child (Appelbaum & Milkman, 2006; Waldfogel, 2001a).

When dealing with the responsibilities of a child with a chronic condition and work, parents may have stress related to the demands of their child and rearranging home and work schedules. According to McCubbin and Patterson (1983), stress may not reach a “crisis” if the family has enough resources to maintain family stability. In addition, under a similar stressor, the family situation may be different depending upon the characteristics of the family and the availability of resources. In particular, McCubbin (1993) conducted empirical research on 47 families who experienced separations because of a prolonged war. Through this longitudinal study, McCubbin developed the Coping with Separation Inventory and theories of coping. The findings of the coping patterns of these families provided a basis for developing interventions in situations such as family separation.

McCubbin and Patterson (1983) advised using the following coping strategies to deal with stressful family situations: (a) avoiding stressors, (b) managing the situation, (c) maintaining the family system’s integrity and morale, (d) developing resources, and (e) implementing structural changes. Working parents with a chronically ill or disabled child may cope in several ways. For instance, some parents

take leave or change a work schedule from full-time to part-time. Other parents may quit their job because of the difficulty of managing multiple roles.

Moreover, low-income or single mothers with a chronically ill child may have more difficulties because one parent must shoulder the responsibility for childcare and work demands. Heymann et al. (1999) used the 1995 Baltimore Parenthood Study to look at 226 parents, 78 of whom were working and residing with children aged 10 years or younger. Using a logistic regression analysis to predict the probability of a parent staying home to care for a sick child, they found that low-income single parents were more likely to stay at work when their children were sick than their married counterparts. Press, Johnson-Dias, and Fagan (2005) used the Philadelphia Survey of Child Care and Work to examine the employment status of adult mothers living in high and medium levels of poverty ( $N = 412$ ). Using a logistic regression model to predict the probability of full-time work, they found that low-income mothers were more likely to have obstacles to full-time work because of childcare problems.

Palmer (1993) conducted a review of previous studies focused on the effects of parents' participation in caring for their sick child while in the hospital, and found benefits of such care for their children's mental health. According to this review, care by parents may have long-term benefits for chronically sick children, particularly children with cystic fibrosis, asthma, and diabetes. Other studies have examined parental coping patterns and health outcomes and found that families with a child with a chronic illness such as cystic fibrosis had greater stress than families that did not have a family member with a chronic condition. These studies focused on family stress without considering the combination of working parents' family- and work-related stress (Bouma & Schweitzer, 1990; McCubbin, McCubbin, Patterson, Cauble,

Wilson, and Warwick, 1983), and the majority of them found benefits of group intervention programs (Brown, Krieg, & Belluck, 1995), positive coping behaviors and attitudes (McCubbin, McCubbin, et al., 1983), and understanding by family members such as siblings (Williams et al., 2002). Many of these studies, including Palmer's, assumed that one of the parents had complete availability to care for their sick child. Few studies of the work-life experience and outcomes for working parents with a chronically ill child include families in which both parents work for pay. Moreover, although work-life management becomes even more difficult during a situation such as a chronic illness, there are few qualitative studies that delve more deeply into the coping strategies adapted by parents who face such situations. Understanding these coping strategies may provide important information that can help families better manage their situations.

The research questions for both components of the present study and the conceptual model and hypotheses for the quantitative study are based on the theories and previous studies described above and are discussed in detail below.

The conceptual model of the relationships among perceived workplace support, perceived supervisory support, work-schedule flexibility, work-life balance, and employee well-being is illustrated in Figure 1. The perception of work-family balance is derived from assessing the extent to which resources enhance the performance of work and family demands (Voydanoff, 2004).

### *Research Questions and Hypotheses*

The primary research questions for this study are as follows. The quantitative study seeks to answer the question, "How are workplace policies related to parents'

work-life balance and well-being in general?” The qualitative study examines the question, “How do working parents cope with the difficulties of having a chronically ill child or a child with a disability in the family?”

Questions and hypotheses specific to the quantitative analysis of the NSCW data are as follows: (a) “To what extent does workplace support influence the well-being of working parents?”; (b) “To what extent does supervisory support influence the well-being of working parents?”; (c) “To what extent does work-schedule flexibility mediate the relationship between informal workplace policies and working parents’ well-being?”; (d) “To what extent does work-life balance mediate the relationship between work-schedule flexibility and working parents’ well-being?”; (e) “To what extent do female and male working parents experience different levels of well-being?”; (f) “To what extent do high- and low-income working parents experience different levels of well-being?”; (g) “To what extent do perceptions of work-schedule flexibility differ between working parents who are single and working parents who live with a spouse or partner?”; and (h) “To what extent do full-time and part-time working parents experience different levels of work-life balance?”

### *Hypotheses*

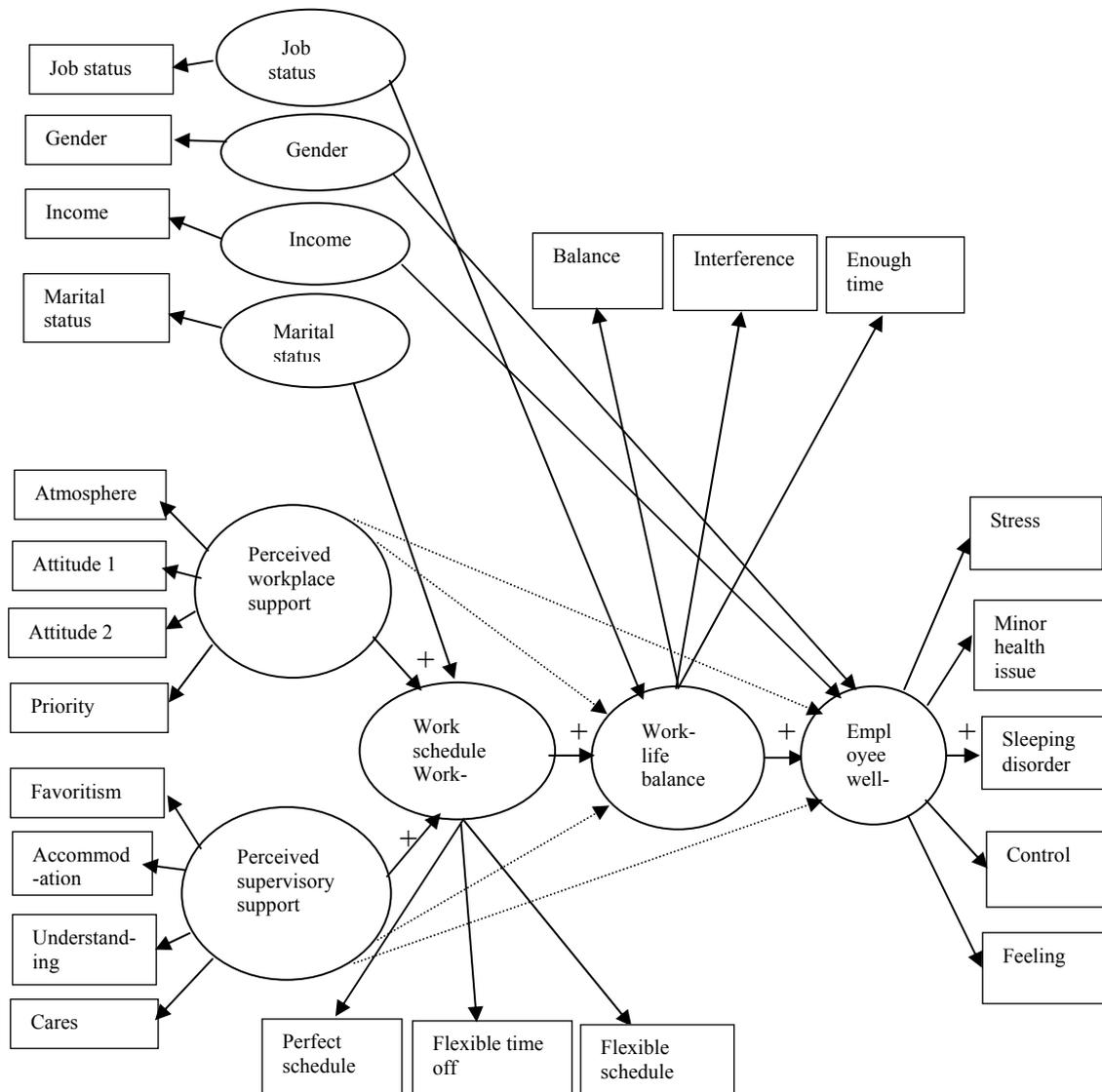
The hypotheses corresponding to the questions above are as follows:

1. Working parents who perceive having a supportive workplace culture will be more likely to report greater work-schedule flexibility than working parents who do not perceive having a supportive workplace culture.
2. Working parents who perceive having a high level of supervisory support will be more likely to report having access to greater work-schedule

flexibility than working parents reporting lower levels of supervisory support.

3. The influence of informal workplace policies on the work-life balance of working parents will be mediated by perceived work-schedule flexibility.
4. The influence of perceived work-schedule flexibility on the well-being of working parents will be mediated by perceived work-life balance.
5. Female working parents will report lower levels of well-being than male working parents.
6. High-income working parents will report higher levels of well-being than low-income working parents.
7. Working parents living with a spouse or partner will report lower levels of perceived job flexibility than single working parents.
8. Part-time working parents will report higher levels of work-life balance than full-time working parents.

Figure 1  
Conceptual model of workplace support, supervisory support, work-schedule flexibility, work-life balance, and employee well-being (+ signifies a positive relationship)



*Note.* Dashed arrows represent relationships that were ultimately dropped to create a more parsimonious model with a better fit to the data.

In short, in the conceptual model (as illustrated in Figure 1), it is proposed that informal supportive policies including perceived workplace support and perceived supervisory support will be related to significant levels of perceived work-schedule flexibility. Work-schedule flexibility is further hypothesized to be associated with

work-life balance. Work-life balance, in turn, is hypothesized to be associated with employee well-being. Finally, in turn, it is conjectured that work-schedule flexibility will be one factor contributing to work-life balance, and work-life balance in turn will be one factor contributing to the well-being of working parents. Therefore, it is hypothesized that (a) the perceptions of work-schedule flexibility will mediate the relationship between informal workplace policies and work-life balance, and (b) work-life balance will mediate the relationship between perceived work-schedule flexibility and employee well-being.

The research questions pertaining to the exploratory qualitative component of the study are: (a) “In what ways do parents of children with a chronic condition manage work demands and care of their child?”; (b) “How do parents cope with work-life situations when they have a child with a chronic condition?”; (c) “What specific role do family work policies play in workers’ perceptions of their work-life balance, stress, and well-being?”; and (d) “How do parents resolve their stress or depression?” These questions are related to the coping strategies that these families use when balancing work and family responsibilities. There are no hypotheses for these questions because the qualitative study is based on inductive constructs.

The second aspect of the qualitative component examines the coping strategies of employees who have a chronically ill or disabled child. Supplementing the quantitative data, in-depth interviews were conducted to examine how working parents cope with work-life balance when they have a child with a chronic illness or disability. We carried out 27 in-depth interviews in New Jersey with parents of children under the age of 18 that have a chronic illness or disability. Based on the conceptual framework of the quantitative study, the in-depth interviews explored parents’ experiences with informal and formal workplace policies such as the FMLA,

work-schedule flexibility, and on-site childcare. In addition, the interview included questions to explore the resources available for and barriers to balancing work-life responsibilities. The questions were also structured to identify coping strategies in managing work-life related stress and depression (see Appendix C).

### *Summary*

This chapter introduced some of the guiding theories for the present research, including family stress theory and border theory, which also includes the concept of boundary-spanning resources. Previous studies on the effects of formal and informal workplace policies have found that if supportive policies are guaranteed and employees are able to use them, then the parents' work-life balance is facilitated. Finally, this chapter presented the research questions for the quantitative and qualitative components of the study, the hypotheses for the quantitative component, and the overall theoretical conceptual model.

## CHAPTER 3: METHODOLOGY

This study utilizes two data sources and methods: a secondary analysis of quantitative data on 1,200 employees with children from the nationally representative 2002 National Study of the Changing Workforce, and qualitative data generated from in-depth interviews with 27 working parents in New Jersey who have a child with a chronic illness or disability.

The mixed methods study was designed to contribute to an understanding of work-life balance and the effects of formal and informal employer-based strategies and supports of parents' well-being. The quantitative study examines the associations among workplace policies and supports and perceived well-being among parents with children. Supplementing the quantitative findings, the in-depth interviews explore how and why parents utilize such supports in the challenging situation of caring for a chronically ill child.

### Research Design

#### *Part I: Secondary Analysis*

##### *Overview*

The quantitative component of the study uses data from the 2002 National Study of the Changing Workforce (NSCW), a nationally representative sample of working adults. Using SEM, the quantitative study examines the relationships that

workplace support and supervisory support have with parents' perceived work-schedule flexibility, work-life balance, and well-being. In this study, employee well-being is an endogenous latent construct. Perceived workplace support and perceived supervisory support are latent exogenous constructs. The mediating variables are employees' perceptions of their work-schedule flexibility and work-life balance.

### *Survey sample*

The NSCW is a survey of the work, personal, and family lives of the U.S. workforce conducted by Harris Interactive, Inc. for the FWI (Bond, Thompson, Galinsky, & Prottas, 2003; FWI, 2004a). The NSCW data is based on a representative sample of the nation's workforce, with surveys conducted every five years. This study uses the 2002 NSCW data (the most recent data available). The total sample consisted of 3,500 employees, including both wage and salaried workers. Because the present research focuses on how employees with children cope with work and life, the total sample for this study consists of 1,200 wage and salaried employees who have children under the age of 18. Research has indicated that employees who have children under age 18 often have difficulty juggling the demands of work and the care of their children (Halpern, 2005). Thus, workplace policies such as workplace support and supervisory support might be associated with perceived work-schedule flexibility, work-life balance, and employee well-being.

### *Survey data collection*

At the time of the survey interview, participants were between the ages of 18 and 64 and were living in non-institutional arrangements in the continental 48 states. The overall response rate was 61%. Respondents were contacted at their home using

random digit dialing. They responded to a survey administered by telephone in either English or Spanish, which took approximately an hour to conduct. They received cash honoraria of \$25 that they could keep or donate to one of seven charities (Bond et al, 2003). The quantitative study received an exemption from the Rutgers University Institutional Review Board (IRB), and the qualitative study received approval from the Rutgers University IRB.

### *Description of the Sample*

Demographic information on the sample is presented in Table 6. The final sample consisted of 1,200 employees, including 692 males (57.7%) and 508 females (42.3%). The sample was made up of primarily White (76.8%), married (72.6%), and full-time (84.8%) working parents. Additional frequencies revealed that 5.3% of the participants provided special assistance or care for a disabled, emotionally disturbed, or seriously ill child.

Table 6  
Survey Respondents' Demographic Information  
N = 1,200

Variable	N	%
Gender		
Male	508	42.3
Female	692	57.7
Race		
White	911	76.8
Black or African American	149	12.6
Native American or Alaskan Native	14	1.2
Asian, Pacific Islander, or Indian	21	1.8
Other, including mixed	91	7.7
Education		
Less than high school	58	4.8
High school or GED	276	23.0
Some college/trade or technical school beyond high school	287	23.9
Two-year Associate's Degree	129	10.8

Variable	N	%
Bachelor's Degree/some college after BA or BS but without graduate degree	310	25.8
Professional degree/Master's Degree or Doctorate	140	11.7
Marital Status		
Single	262	21.9
Living with partner	66	5.5
Married	867	72.6
Job status		
Full-time	1,017	84.8
Part-time	183	15.2
Provide special assistance or care for a disabled, emotionally disturbed, or seriously ill child in your home		
Yes	63	5.3
No	1,135	94.7

### *Measures*

#### *Endogenous latent constructs: Employee well-being*

This latent construct was measured with five items based on the following questions asked to the respondents: (a) "How often have you felt nervous or stressed in the past month?"; (b) "Have you been bothered by minor health problems such as headaches, insomnia, or stomach upsets in the past month?"; (c) "How often have you had trouble sleeping to the point that it affected your performance on and off the job in the past month?"; (d) "How often have you felt that you were unable to control the important things in your life in the past month?"; and (e) "How often have you felt that difficulties were piling up so high that you could not overcome them in the past month?" The response values ranged from 1 (*never*) to 5 (*very often*). These items were reverse coded so that higher values on the scale indicated greater well-being. This measure was chosen as it had been previously used to assess stress (Behson, 2005) and well-being (Nomaguchi, Milkie, & Bianchi, 2005). The items are predictive of clinical depression according to psychiatric screening criteria (FWI, 2002). For the present study, the coefficient alpha of well-being (N=1,200) was .76.

*Mediating variable: Work-life balance*

The latent construct of work-life balance was measured with three items, which were derived from responses to the following three questions in the survey:

1. “How much do your job and your family life interfere with each other?”

For this question, the response values ranged from 1 (*a lot*) to 4 (*not at all*). This item was previously used to assess work-life conflict (Winslow, 2005).

2. “How easy or difficult is it for you to manage the demands of your work

and your personal or family life?” The response values ranged from 1 (*very easy*) to 5 (*very difficult*). Items were reverse coded so that higher values on the scale indicated greater work-life balance. This item was chosen because it had been previously used to assess work-life balance in a study of IBM’s (International Business Machines) employees (Hill et al., 2001).

3. “How often have you not had enough time for your family or other important people in your life because of your job?” This variable has five response values ranging from 1 (*very often*) to 4 (*never*). As mentioned earlier, this item is often used as a measure of role conflict or work-family conflict in previous studies (Emslie et al., 2004). Because the term work-life balance has varied over time, there are no studies using consistent items. For the present study, the coefficient alpha of work-life balance using the three items above (N=1,200) was .75. Items were reverse coded so that higher values on the scale indicated greater work-life balance.

*Mediating variable: Work-schedule flexibility*

This latent construct was measured with three items based on the three following survey questions.

1. “How much control would you say have in scheduling your work hours?”  
The response values ranged from 1 (*complete*) to 5 (*none*). This item was chosen as it had been previously used to assess scheduling flexibility (Hill et al., 2001; Keene & Reynolds, 2005).
2. “Is this schedule perfect for you, okay but could be better, not very good, or not at all what you want?” The response values ranged from 1 (*perfect for you*) to 4 (*not at all what you want*). Items were reverse coded so that higher values on the scale indicated better schedules.
3. “How hard is it for you to take time off during your workday to take care of personal or family matters: very hard, somewhat hard, not too hard, or not at all hard?” The response values ranged from 1 (*very hard*) to 4 (*not at all hard*). Items were reverse coded so that higher values on the scale indicated greater perceived work-schedule flexibility. For the present study, the coefficient alpha of work-schedule flexibility (N=1,200) was .52.

*Exogenous latent constructs: Perceived workplace support*

This latent construct was measured with four items, which were based on the respondents’ level of agreement with the following statements: (a) “There is an unwritten rule at my place of employment that you can’t take care of family needs on company time”; (b) “At my place of employment, employees who put their family or personal needs ahead of their jobs are not looked upon favorably”; (c) “If you have a

problem managing your work and family responsibilities, the attitude at my place of employment is ‘You made your bed, now lie in it!’”; and (d) “At my place of employment, employees have to choose between advancing in their jobs or devoting attention to their family or personal lives.” Responses ranged from 1 (*strongly agree*) to 4 (*strongly disagree*). Higher values on the scale indicate that the workplace is more supportive of the employee’s family responsibilities. This measure was chosen as it had been previously used to assess family support environment (Mennino et al., 2005; Prottas, 2005) (scale alpha value of .74) and family oriented workplace policies (Hegtvedt, Clay-Warner, & Ferrigno, 2006) (scale alpha value of .73) using the 1997 NSCW data. In the present study, the alpha coefficient of perceived workplace support ( $N = 1,200$ ) was .72.

*Exogenous latent constructs: Perceived supervisory support*

This latent construct was measured with four items, which were based on the respondents’ level of agreement with the following statements: (a) “My supervisor or manager is fair and doesn’t show favoritism in responding to employees’ personal or family needs”; (b) “My supervisor or manager accommodates me when I have family or personal business to take care of, for example, medical appointments, meeting with child’s teacher, etc.”; (c) “My supervisor or manager is understanding when I talk about personal or family issues that affect my work.”; and (d) “My supervisor or manager really cares about the effects that work demands have on my personal family life.” Responses ranged from 1 (*strongly agree*) to 4 (*strongly disagree*). Items were reverse coded so that higher values on the scale indicated greater supervisory support. This measure was chosen as it had been previously used to assess supervisory support

(Behson, 2005; Mennino et al., 2005; Prottas, 2005) (scale alpha of .86). For the present study, the alpha of perceived supervisory support ( $N = 1,200$ ) was .83.

#### *Control variables*

Gender, marital status, income, and job status were used as control variables. Gender is represented in the model as female (coded as 1) and male (coded as 0). Many previous studies have found that gender is a predictor of differences in work-home/family conflict (Emslie et al., 2004; Higgins et al., 1994) and feelings about work-family balance (Keene & Quadagno, 2004; Milkie and Peltola, 1999; Scandura & Lankau, 1997; Williams, 2000). Several studies have found that women experience more role conflict as a worker and mother than men experience with their work-family roles (Guest, 2002). Regarding the effects of such conflicts, Emslie et al. (2004) and Rosenfield (1989) found that work-home conflict was associated with mental health problems. In particular, Rosenfield found that working mothers had more mental health problems than men and that personal control was a key mediating variable in the relationships between various demands (including work and care responsibilities) and symptoms. MacDonald, et al., (2005) found that women had more stress about childcare. Thus, the present study hypothesizes that working mothers will be less likely to report high levels of well-being than working fathers.

Marital status is a binary variable (recoded as 0 = single, 1 = married or living with a partner). According to previous studies, working mothers who have children under age 18 often may have more difficulty managing work-life balance than working fathers because of gender roles that dictate that women have the primary responsibility for children and household chores (Barnett, 2004; Barnett & Hyde,

2001; Gerson, 2002). Thus, it is hypothesized that working parents living with a spouse or partner will be less likely to report higher levels of perceived job flexibility.

Respondents reported their yearly household income (recoded as 1 = \$20,000/year or less, 2 = \$20,000 to \$49,999, 3 = \$50,000 to \$94,999, 4 = \$95,000 or more). Lower income employees, especially single mothers, have more difficulties in balancing work and family responsibilities (Barnett, et al., 2003). Thus, it is hypothesized that high-income working parents are more likely to report higher levels of well-being than low-income working parents.

Job status is represented in the model as part-time employees (value of 0) and full-time employees (value of 1). Respondents' job status was self-reported because there was no standard definition of how many hours constituted full-time and part-time status. Some women choose to work part-time because it is likely to enable them to balance work-family more easily. However, part-time work tends to be less well-paid as well as less secure than full-time work (Evans, 2002). In the present study, it is hypothesized that part-time working parents will be more likely to report higher levels of work-life balance than full-time working parents.

### *Survey Data Analysis*

Quantitative data were entered into statistical software, LSREL Version 8.50, and various tests were run including confirmatory factor analysis and SEM. The confirmatory factor analysis tested whether the factor structure of the latent variables in previous studies actually reflected what the factors intended to measure. The confirmatory analysis strengthens the validity of the measurement model by reducing measurement error by using multiple observed variables per latent variable. Next, we tested the SEM to examine the structural model using LSREL 8.50 (Joreskog &

Sorbom, 1996). SEM is a multivariable technique that allows the researcher to discover the extent to which a specific theoretical model is consistent with the available data. The construct validity and causal relationships were considered in the present study with SEM. In addition, with SEM, measurement error was considered in the estimation of the model and all relationships were based on the guiding theories and examined simultaneously.

The primary interest in this study is in the associations between boundary-spanning resources such as perceived workplace support, supervisory support, and work-schedule flexibility. In addition, the analyses examined whether work-schedule flexibility and work-life balance were potential mediators of these relationships. The model was corrected according to the modification indices in order to find the most adjusted model. In this process, paths with a *t*-value of 2.0 or greater were used to indicate approximate significance. Regarding model fit statistics, SEM relies on several statistical tests such as the normed fit index (NFI), the non-normed fit index (NNFI), the comparative fit index (CFI), the root mean square error of approximation (RMSEA), the goodness-of-fit Index (GFI), the adjusted goodness-of-fit index (AGFI), and chi square tests. The *p*-value for chi-square tests must be larger than .05 to decide that the theoretical model fits the data. Acceptable model fit is indicated by a CFI value of .90 or greater (Hair, Anderson, Tathan, & Black, 1998; Hu & Bentler, 1999). Acceptable model fit is indicated by an RMSEA value of .06 or less (Hu & Bentler, 1999). Similarly, alternative measures of fit, such as the NFI, the NNFI, the GFI, and the AGFI are considered acceptable if above .90 (Hu & Bentler, 1999; Kaplan, 2000).

## *Part II: In-depth Interviews*

### *Overview*

The qualitative component of this study included 27 in-depth interviews in New Jersey with working parents that have children who are chronically ill or disabled. The interview questions were related to a variety of strategies that these parents had adopted to manage this situation, including those that facilitated a balance of work and family responsibilities.

### *In-depth interviews: Sample*

The research focused on currently or recently employed parents with a child under the age of 18 who had a serious chronic illness or disability and who had had this condition for two or more years. The researchers contacted the following organizations that provide social services for such children and/or their parents: Special Children Services, the Cystic Fibrosis Foundation, the Child Life Program of Robert Wood Johnson Children's Hospital, the Allergy & Asthma Network, Montclair University's Child Life Specialist Program, the Child Life Council of Greater NY, the Association for Children of NJ, the National Caregivers Association, and the Rutgers University School of Social Work. These organizations circulated flyers about the study to their clients, and the parents contacted the author by phone or e-mail. Additional respondents were obtained via a snowball sampling method by asking each interviewed person to suggest other people to interview. The following criteria were applied to screen for participation: (a) Parent is currently employed or was employed at some time in the past 12 months, (b) child has a serious chronic illness or disability that has lasted three months or more, and (c) child was diagnosed two or more years ago.

*In-depth interviews: Data collection*

Data collection took place in two stages. First, we developed a 20-minute questionnaire that allowed parents to quickly check off the answers that applied to them with regard to personal characteristics, job and work experiences, the company's policies, the child's condition, care responsibilities, and leave experiences (See Appendix B). Second, we conducted a longer interview with the parent who had completed the questionnaire and who indicated her or his willingness to be interviewed (See Appendix C). The participants in this study received a \$35 gift certificate for Target or American Express. The study received approval from the Rutgers University IRB.

The interviews were highly focused on the topic of work-life experiences. The topics explored included responsibilities related to work and to caring for a child with a chronic condition; employer policies including flexibility, paid/unpaid leave, care services, sources of help (relatives or friends or neighbors); work-life satisfaction; and emotional well-being and health. The main themes were explored from the respondents' responses to questions on these topics. This study was designed to contribute to our understanding of how parents cope with the demands of work and family responsibilities, and what challenges they face in doing so. While work-life balance is a challenge for most employees, this is especially true for parents who have a child with a chronic health condition such as asthma or cystic fibrosis.

The interviews averaged 1.5 hours in length and were conducted between February 2006 and July 2007 by the author and a research assistant who was trained for the study. Before interviewing the respondents, the researchers asked each respondent to read and sign a letter of consent (See Appendices D and E). The

researchers interviewed the parents at a café, restaurant, one of the researcher's offices, or the respondent's office, according to their preference. While the author was interviewing the parents, the co-researcher created a typewritten transcript on her computer. At the same time the interview was recorded with a tape recorder. The co-researcher identified anything that was missed in the initial transcript immediately after the interview by reviewing the tapes.

The interviews were semi-structured with open-ended questions. The questions were organized according to six categories, including work-family policies, leave experience, work-life satisfaction, mood, and emotional well-being and health. In addition, the interview included an opening and closing question regarding future life expectations. The interview began with relatively non-threatening questions about the interviewee's current job position. Throughout the interview, the researchers used non-directive probes for details (e.g., "Can you tell me some more?" "Why?" "What happened next?"). The questionnaire was developed by the author in conjunction with Dr. Eileen Appelbaum based on issues identified in the research literature. The Rutgers University 2005 President's Research in Service to New Jersey Award provided funds for the study to examine family leave and work-life balance of New Jersey parents of children with chronic conditions.

#### *Description of the Sample*

The total sample consisted of 27 working parents, defined as those who work on payroll for someone else and who have a child with a chronic condition.

Participants were between the ages of 30 and 60 and living in New Jersey. All demographic information for the survey can be found in Table 7. The sample consisted primarily of White married women who were highly educated and between

the ages of 41 and 60. Four families were headed by single parents (all headed by mothers).

Table 7  
Survey Respondents' Demographic Information  
*N* = 27

Variable	<i>N</i>	<i>F</i>
Gender		
Male	2	7.4
Female	25	92.6
Race		
White	20	74.1
Black	4	14.8
Asian	2	7.4
Hispanic	1	3.7
Education		
High school graduate or GED	2	7.4
Some College, Associate's Degree or technical training	4	14.8
College graduate (Bachelor's Degree)	10	37.0
Graduate or Professional school	11	40.7
Marital Status		
Married	20	74.1
Living with a partner	2	7.4
Divorced	3	11.1
Separated	1	3.7
Never married	1	3.7
Age		
30-40	9	52.9
41-50	14	51.9
51-60	4	14.8

### *In-depth Interviews*

Table 8 shows the characteristics of the children of the participants we interviewed. The median age of the children was 9. Thirteen of the children had a chronic physical illness such as cystic fibrosis, asthma, or pulmonary hypertension, and nine had a cognitive disability such as autism, Asperger's syndrome, or other cognitive developmental issues. Five parents had children with both physical and

cognitive conditions. Parents who have a chronically ill child with conditions such as asthma or cystic fibrosis typically need persistent supervision including medical care. Parents who have a child with a disability or another chronic condition such as autism usually need persistent supervision. These parents have similar experiences in terms of having a child with a chronic condition. However, according to their child's characteristics, such as the degree of medical care needed, the child's age, and the severity of the condition, parents may have different experiences, utilize different coping strategies and experience different life adjustment. The chronic conditions of the participants' children that we interviewed for the study included cystic fibrosis, asthma, autism/Asperger's syndrome, epilepsy/seizures, cognitive disabilities, learning disabilities, and HIV. Other conditions included having multiple handicaps (i.e., being multiply disabled) such as transverse myelitis and short-gut syndrome. Case G had a daughter with multiple handicaps that couldn't speak and needed assistance with essentially every task and activity. Case A had a daughter with a condition called transverse myelitis, which is a neurological disorder that includes chronic respiratory problems. Case U had a daughter with short-gut syndrome, which results in rapid dehydration.

Table 8  
Selected Characteristics of Respondents' Children  
*N* = 27

Case code	Respondents' gender	Child's age	Child's sex	Child's condition
A	Female	7	Male,	Asthma, Transverse myelitis
		4	Female	
B	Female	18	Male	Cystic Fibrosis
C	Female	8	Female	Cystic Fibrosis
D	Female	2	Female	Cognitive development issues
E	Female	14	Female	Kidney disease, Autism (ADD & ADHD)
F	Female	12	Female	HIV
G	Female	13	Female	Multiple handicaps
H	Male	14	Female	Cystic Fibrosis

Case code	Respondents' gender	Child's age	Child's sex	Child's condition
I	Female	16	Female,	Diabetes, Cystic Fibrosis
		13	Male	
J	Female	9	Male	Autism
K	Female	12	Male	Autism(PDD, ADHD, Asperger's syndrome)
L	Female	20	Male	Down syndrome
M	Female	17	Female	Learning disability, ADHD, special IEP, Asthma
N	Female	12	Male	Asperger's Syndrome
O	Female	9	Female	Pulmonary hypertension & Asthma
P	Female	9	Male	Asthma
Q	Female	15	Female	Epilepsy & history of seizures
R	Female	9	Male	Autism & Asthma
S	Female	18	Female	Seizures disorder & multiply disabled
T	Female	8	Male	Autistic with PDDMRS
U	Female	3	Female	Short-gut syndrome
V	Female	2	Male	Neurology problems; kidney reflex; duplicate thumbs; born with Hi-low blood sugar
W	Female	16	Female	Cognitive disabilities
X	Male	2	Female	Severe allergies
Y	Female	10	Male	Asthma & Allergies
Z	Female	11	Female	Learning disabilities
AA	Female	18	Male	Argininosuccinate Lyase Deficiency

As shown in Table 9, almost half of the parents had a part-time job at the time of the interview. Approximately half of the parents worked in an establishment with less than 50 employees. Therefore, many parents were not eligible to use FMLA leave because the law requires the workplace to have 50 or more employees in order for it to be eligible. Accordingly, even though many parents knew about the FMLA, only a few parents had been able to use it.

Table 9  
 Respondents' knowledge of leave policy and leave experience

*N* = 27

Case code	Number of employees at respondent's job	Respondent's knowledge of FMLA	Knowledge of NJFLA	Leave experience	Current work status
A	1-4	Yes	Yes	No	Full-time
B	5-49	Yes	No	No	Part-time
C	1-4	Yes	Yes	No	Full-time
D	5-49 & 40-499	Yes	Yes	No	Two part-time
E	50-499	Yes	Yes	Yes	Full-time
F	5-49	No	No	No	Part-time
G	500 or more	Yes	Yes	No	Part-time
H	5-49	Yes	No	Yes <sup>a</sup>	Full-time
I	5-49	Yes	No	No	Part-time
J	50-499	Yes	Yes	Yes	Full-time
K	1-4	Yes	No	No	Part-time
L	50-499	Yes	Yes	Yes	Full-time
M	50-499	Yes	Yes	Yes	Full-time
N	500 or more	Yes	Yes	Yes	Part-time
O	5-49	Yes	Yes	No	Full-time
P	50-499	Yes	Yes	No	Full-time
Q	50-499	Yes	Yes	No	Full-time
R	50-499	No	No	No	Part-time
S	50-499	Yes	Yes	No	Part-time
T	5-49	No	No	No	Part-time
U	50-499	Yes	Yes	Yes	Part-time
V	5-49	Yes	Yes	No	Part-time
W	5-49	Yes	No	No	Full-time
X	5-49	Yes	No	No	Full-time
Y	500 or more	Yes	No	No	Part-time
Z <sup>b</sup>	1-4	Yes	No	No	Full-time
AA	5-49	Yes	No	No	Full-time

*Note.* <sup>a</sup>Case H, who worked for a small company, had an "FMLA-type leave."

<sup>b</sup>Case Z was unemployed, so the data represent the characteristics of her most recent job.

#### *Data analysis of In-depth Interviews*

The qualitative information from the in-depth interviews were coded by searching for common themes. Two questionnaires were developed for the qualitative research: (a) a short, 56-item questionnaire that solicited information on

demographics, work environment, family conditions, and the chronically ill child's situation; and (b) a second, in-depth interview which examined work-life conflicts and the coping strategies of parents with a chronically ill or disabled child through open-ended questions. The first questionnaire provided descriptive analyses including means and percentages on demographic variables, satisfaction with employment policies, and information on the individual's care responsibilities including the status of the chronically ill child's condition. The second questionnaire used in-depth interviews to analyze the work-life experiences of parents who had a child with a chronic condition. We examined the main themes that surfaced about the difficulties that the respondents experienced in managing their work and family responsibilities, and the formal and informal policies and resources that helped them cope with these difficulties. We analyzed the interviews based on grounded theory using a coding system that was developed by Glaser and Strauss (1967) and others (Berg, 1998), which includes open coding, axial coding, and selective coding. The uses of these three coding methods are explained below.

The author first conducted open coding to explore all possible patterns in the data and factors affecting those patterns. Specifically, using the questions on the interview schedule as sensitizing concepts, open coding was used to (a) examine a specific and consistent set of questions, (b) analyze the data minutely, (c) interrupt the coding to write theoretical notes, and (d) never assume the analytic relevance of any traditional variable such as age, sex, social class, and so forth until the data showed it to be relevant (Berg, 1998; Strauss, 1987). Next, the author developed categories from the transcripts based on the major topics of the in-depth interview. Axial coding was conducted to create key categories and make explicit connections between categories and sub-categories such as the use of work and family polices. The author produced a

list of key categories such as work-schedule flexibility, supervisory support, and childcare services.

Finally, selective coding was conducted to identify the core categories, including indigenous themes that emerged from the data but had been unanticipated such as social support experiences. Content analysis was accomplished by the author through the use of coding frames. The coding frames were used to organize the data and identify concepts and themes after open coding was completed. This coding helped to identify categories or themes based upon patterns and ideas that emerged from the data in the interviews. As strategies for enhancing the quality of the analysis, an analysis of the negative cases was used, which involved parents' positive reactions to their child's diagnosis. Design checks were also used in order to keep the methods and data in context; this involved checking and confirming that the quotations were specified in enough detail (Patton, 2002). In addition, peer debriefing was used, which involved exchanges of ideas with research colleagues that were involved in the study (Lincoln & Guba, 1985; Tashakkori & Teddlie, 1998). After analyzing the key themes from the data, the author received feedback from researchers with substantive knowledge in the research area through attending a conference and communicating by e-mail.

## CHAPTER 4: RESULTS

This chapter presents the results of the analyses and the model tests described in the previous chapter. The chapter begins with descriptive statistics including means, standard deviations, and correlations for the variables. Then, confirmatory factor analysis is presented to show the fit of the five-factor model. Next, the SEM results are shown with the fit indices. Finally, the major themes of the in-depth interviews are presented.

### Part I-Quantitative Study

#### *Descriptive Statistics*

Descriptive statistics were run to show the overall directions and degrees of the hypothesized relationships. Correlations for all of the measures are shown in Table 10 along with the means and standard deviations for all variables in the model. In general, the correlations of the study variables were in the expected directions. For each of the five constructs (work-schedule flexibility, workplace support, supervisory support, work-life balance, and employee well-being) most of the indicators were correlated with each other. The correlation between the supervisory support measures ‘supervisor cares’ and ‘supervisor is understanding’ was the highest of all the relationships between the variables,  $r = .68, p < .01$ .

Table 10  
Means, Standard Deviations, and Correlations for the Variables  
( $N = 980$ )

Variable	<i>M</i>	<i>SD</i>	1. FH	2. FO	3. PH	4. AM	5. A1	6. A2	7. PO	8. FV	9. AD
1.Flexible hour(FH)	2.92	1.37	1.00								
2.Flexible off (FO)	2.67	1.03	0.26 **	1.00							
3.Perfect hour(PH)	3.45	0.67	0.27 **	0.28 **	1.00						
4.Atmospher e(AM)	3.00	1.05	0.20 **	0.31 **	0.22 **	1.00					
5.Attitude1 (A1)	2.93	1.01	0.09 **	0.22 **	0.21 **	0.41 **	1.00				
6.Attitude2 (A2)	3.19	1.00	0.16 **	0.22 **	0.26 **	0.37 **	0.43 **	1.00			
7.Priority (PO)	2.83	1.05	0.08 **	0.17 **	0.17 **	0.33 **	0.41 **	0.39 **	1.00		
8.Favoritism (PV)	3.28	0.91	0.18 **	0.31 **	0.19 **	0.27 **	0.33 **	0.32 **	0.26 **	1.00	
9.Accommo dation(AD)	3.55	0.76	0.24 **	0.40 **	0.24 **	0.36 **	0.36 **	0.38 **	0.26 **	0.52 **	1.00
10.Understa nding(US)	3.39	0.83	0.22 **	0.32 **	0.23 **	0.31 **	0.37 **	0.37 **	0.25 **	0.58 **	0.60 **
11.Cares (CA)	3.11	0.95	0.22 **	0.30 **	0.24 **	0.33 **	0.34 **	0.35 **	0.23 **	0.60 **	0.57 **
12.Balance (BA)	3.26	0.88	0.13 **	0.29 **	0.29 **	0.20 **	0.22 **	0.14 **	0.15 **	0.20 **	0.22 **
13.Interferen ce(IF)	2.52	0.96	0.09 **	0.29 **	0.33 **	0.19 **	0.20 **	0.16 **	0.17 **	0.17 **	0.21 **
14.Enough time(ET)	3.35	1.12	0.11 **	0.28 **	0.29 **	0.16 **	0.23 **	0.19 **	0.19 **	0.23 **	0.25 **
15.Stress (ST)	2.99	1.26	0.03	0.18 **	0.14 **	0.11 **	0.16 **	0.09 **	0.0 7*	0.15 **	0.18 **
16.Minor health(MH)	3.61	1.27	0.02	0.13 **	0.09 **	0.08 **	0.13 **	0.06 **	0.0 4*	0.1 4*	0.12 **
17.Sleeping disorder (SD)	4.09	1.11	0.06 *	0.14 **	0.16 **	0.12 **	0.16 **	0.11 **	0.13 **	0.16 **	0.13 **
18.Cntrol (CO)	3.74	1.18	0.03	0.12 **	0.12 **	0.09 **	0.13 **	0.06 **	0.0 8*	0.14 **	0.16 **
19.Feeling (FE)	3.96	1.11	0.05	0.15 **	0.16 **	0.13 **	0.15 **	0.15 **	0.11 **	0.22 **	0.18 **

Variable	<i>M</i>	<i>SD</i>	10. US	11. CA	12. BA	13. IF	14. ET	15. ST	16. MH	17. SD	18. CO	19. FE
10.Understanding (US)	3.39	0.83	1.00									
11.Cares (CA)	3.11	0.95	0.68 **	1.00								
12.Balance (BA)	3.26	0.88	0.24 **	0.24 **	1.00							
13.Interference (IF)	2.52	0.96	0.20 **	0.23 **	0.50 **	1.00						
14.Enough time(ET)	3.35	1.12	0.27 **	0.29 **	0.43 **	0.53 **	1.00					
15.Stress (ST)	2.99	1.26	0.14 **	0.20 **	0.36 **	0.25 **	0.31 **	1.00				
16.Minor health (MH)	3.61	1.27	0.16 **	0.13 **	0.18 **	0.15 **	0.19 **	0.39 **	1.00			
17.Sleeping disorder (SD)	4.09	1.11	0.13 **	0.14 **	0.23 **	0.23 **	0.27 **	0.35 **	0.41 **	1.00		
18.Control (CO)	3.74	1.18	0.12 **	0.15 **	0.22 **	0.16 **	0.23 **	0.40 **	0.25 **	0.31 **	1.00	
19.Feeling (FE)	3.96	1.11	0.14 **	0.18 **	0.26 **	0.14 **	0.22 **	0.49 **	0.28 **	0.36 **	0.43 **	1.00

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

### Confirmatory Factor Analysis

A confirmatory factor analysis was performed to determine the fit of the previously identified five-factor model. In this step, the factors were inspected consecutively to determine which model had the best fit to the data. The results show that none of the one-factor, two-factor, three-factor, or four-factor models provided an appropriate fit for the data. Furthermore, examination of the fit indices revealed that the five-factor model had the best fit to the data as shown in Table 11.

Table 11  
Goodness of fit indices for the confirmatory factor structures

	Models tested				
	Five factor	Four factor	Three factor	Two factor	One factor
$\chi^2$	365.48* (df = 142)	750.61* (df = 146)	910.82* (df = 149)	1447.84* (df = 151)	2888.37* (df = 152)
CFI	0.957	0.905	0.879	0.809	0.763
NNFI	0.949	0.888	0.861	0.783	0.602
RMSEA	0.040 (0.035- 0.045)a	0.065 (0.060- 0.070)a	0.072 (0.068- 0.077)a	0.094 (0.089- 0.098)a	0.113 (0.131- 0.141)a

Note. \* $p < .001$

a 90% population confidence interval.  $\chi^2$ , chi-square; CFI, comparative fit index; NNFI, non-normed fit index; RMSEA, root mean squared error of approximation.

All measured variables initially specified in our factors were included in the confirmatory factor analysis based on the magnitude of individual loadings. Previous research has treated variables with loadings less than .32 as poor and excluded them from the factor analysis (Comrey & Lee, 1992). The result for the equation model was  $\chi^2 = 365, p < .001; \chi^2/df = 2.6$ . The five-factor model was also shown to have a good fit to the data with other fit measures, with a Goodness of Fit Index of .96, a Root Mean Square Residual of .03, a Normed Fit Index of .93, an Incremental Fit Index of .96, and a Relative Fit Index of .92. All variables specified in the factors met the

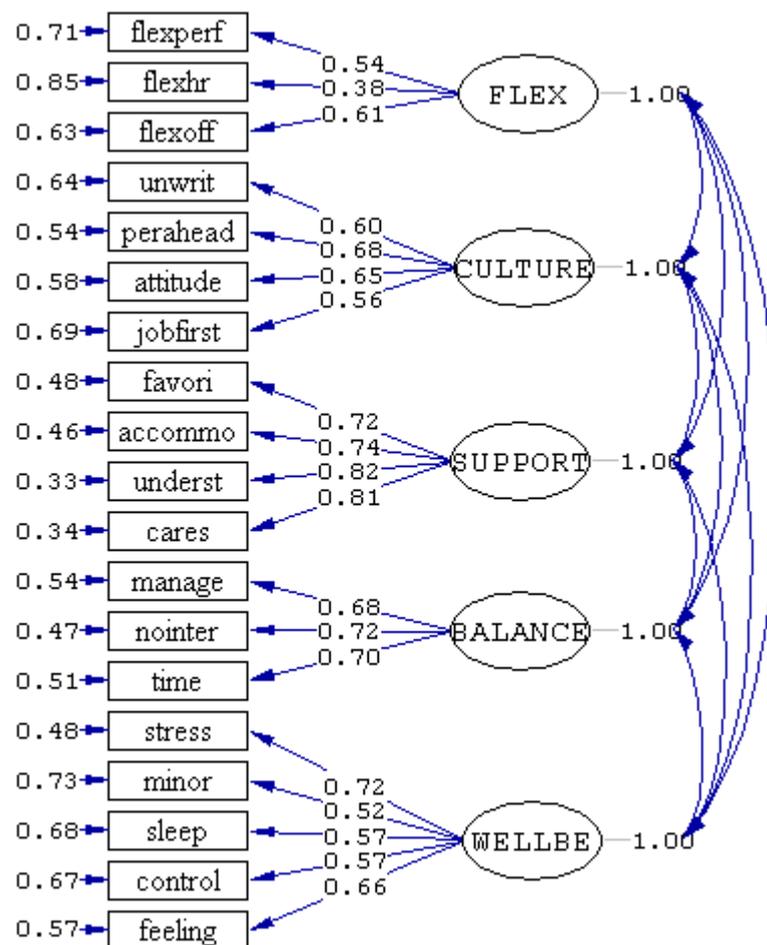
minimum threshold for an acceptable loading value, with loadings of less than .32.

The confirmatory factor analysis results are presented in Table 12, Table 13 and

Figure 2. Because satisfactory fit had been achieved in the confirmatory factor

analysis, the next step was to perform the SEM analysis.

Figure 2  
Confirmatory Factor Analysis



*Note.* Latent variables: flex = work-schedule flexibility; culture = perceived workplace support; support = perceived supervisory support; balance = work-life balance; wellbe = well-being.

Observed variables: flexperf = perfect hour; flexhr = flexible hour; flexoff = flexible off; unwrit = atmosphere; perahead = attitude 1; attitude = attitude 2; jobfirst = priority; favori = favoritism; accommo = accommodation; underst = understanding; cares = cares; manage = balance; nointer = interference; time = enough time; stress = stress; minor = minor health; sleep = sleeping disorder; control = control; feeling = feeling.

Table 12  
Confirmatory Factor Analysis

Item	Factor loadings				
	1	2	3	4	5
<b><i>Work-Schedule Flexibility</i></b>					
How much control would you say you have in scheduling your work hours: complete control, a lot, some, very little, or none?	0.38				
How hard is it for you to take time off during your work day to take care of personal or family matters: very hard, somewhat hard, not too hard, or not at all hard?	0.61				
Is this schedule perfect for you, okay but could be better, not very good, or not at all what you want?	0.54				
<b><i>Workplace Support</i></b>					
There is an unwritten rule at my place of employment that you can't take care of family needs on company time.		0.60			
At my place of employment, employees who put their family or personal needs ahead of their jobs are not looked upon favorably.		0.68			
If you have a problem managing your work and family responsibilities, the attitude at my place of employment is, "You made your bed, now lie in it!"		0.65			
At my place of employment, employees have to choose between advancing in their jobs or devoting attention to their family or personal lives.		0.56			
<b><i>Supervisory Support</i></b>					
My supervisor or manager is fair and doesn't show favoritism in responding to employees' personal or family needs.			0.72		
My supervisor or manager accommodates me when I have family or personal business to take care of: for example, medical appointments, meeting with the child's teacher, etc.			0.74		
My supervisor or manager is understanding when I talk about personal or family issues that affect my work.			0.82		
My supervisor or manager really cares about the effects that work demands have on my personal family life.			0.81		
<b><i>Work-Life Balance</i></b>					
How easy or difficult is it for you to manage the demands of your work and your personal or family life?				0.68	

Item	Factor loadings				
	1	2	3	4	5
How much do your job and your family life interfere with each other?				0.72	
How often have you not had enough time for your family or other important people in your life because of your job?				0.70	
<b>Well-Being</b>					
How often have you felt nervous and stressed in the past month?					0.72
Have you been bothered by minor health problems such as headaches, insomnia, or stomach upsets in the past month?					0.52
How often have you had trouble sleeping to the point that it affected your performance on or off the job in the past month?					0.57
How often have you felt that you were unable to control the important things in your life in the past month?					0.57
How often have you felt that difficulties were piling up so high that you could not overcome them in the past month?					0.66

*Note:* Factor 1: work-schedule flexibility; Factor 2: perceived workplace support; Factor 3: perceived supervisory support; Factor 4: work-life balance; Factor 5: employee well-being.

Table 13  
Goodness of fit indices for the confirmatory factor structures

Index	Models tested Five factor
$\chi^2$	365.48*( <i>df</i> = 142)
CFI	0.96
GFI	0.96
IFI	0.96
NFI	0.93
RFI	0.92
NNFI	0.95
RMR	0.03
RMSEA	0.040(0.035-0.045) <sup>a</sup>

Note. \**p*<0.001

<sup>a</sup> a 90% population confidence interval.

Factor correlation results are presented in Table 14. The correlations between factors were moderate ( $r < .85$ ), indicating that there was discriminate validity.

Table 14  
Factor correlation

	Flexibility	Culture	Support	Balance	Well-being
Flexibility	1.0				
Culture	.61	1.0			
Support	.65	.66	1.0		
Balance	.68	.42	.42	1.0	
Well-being	.36	.29	.32	.53	1.0

Note. Latent variables: flexibility = flexible work schedule; culture = perceived workplace support; support = perceived supervisory support; balance = work-life balance; well-being = employee well-being.

### *Structural Equation Model*

SEM was used to examine the mediator models. Perceived workplace support was examined with four indicator questions, perceived supervisory support with four indicator questions, work-schedule flexibility with three indicator questions, work-life balance with three indicator questions, and employee well-being with five indicator

questions. As many previous studies have found, perceived workplace support, perceived supervisory support, and work-schedule flexibility were associated with employees' perceived levels of work-life balance (Behson, 2005; Frye & Breaugh, 2004; Secret & Sprang, 2001; Warren & Johnson, 1995). Several researchers have found that perceived workplace support and perceived supervisory support are associated with the use of work-schedule flexibility (Secret & Sprang, 2001; Warren & Johnson, 1995). However, little is known about the associations between these variables and the potential mediators of any such relationships. Thus, mediation effects were examined in the model. These effects are shown in Figures 3, 4, 5, and 6, with circles representing the latent variables and rectangles representing the measured variables.

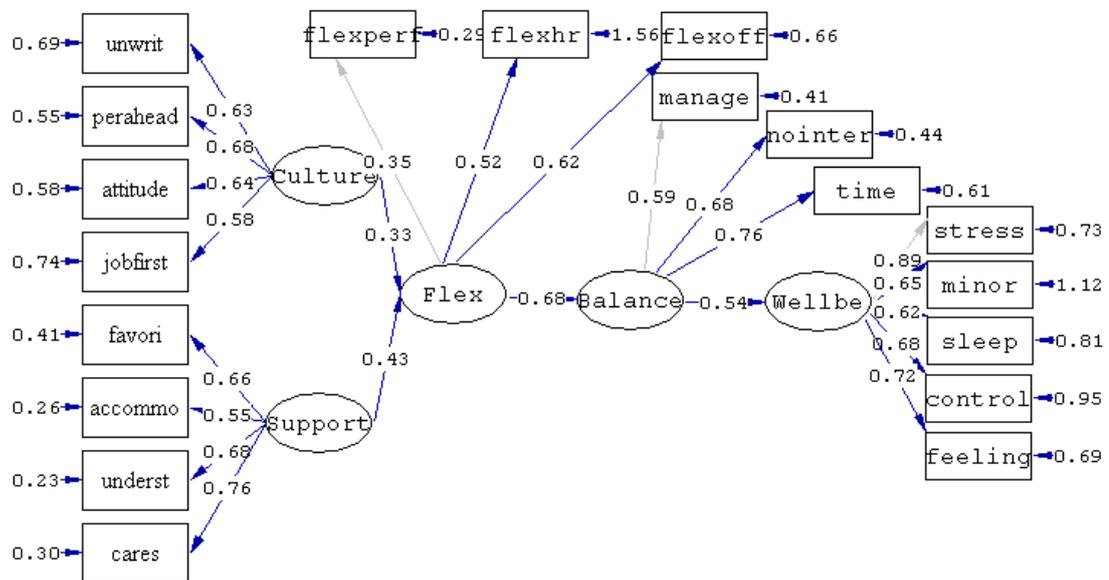
According to Hombeck (1997), three models must be estimated to test for mediation effects in SEM. Because the present model has two latent variables rather than one, two more steps are required to specify the fully and partially mediated models. The first model (the direct model) tests the effects of the predictors (i.e., workplace support and supervisory support) on the criterion (work-life balance) in the absence of the mediators (work-schedule flexibility and work-life balance). This test was also repeated with well-being as the criterion.

For the mediation to exist, the path coefficients (from workplace support and supervisory support to work-life balance, and from workplace support and supervisory support to well-being) in the direct-effect models must be significant. Therefore, if the path coefficient from workplace support and supervisory support to work-life balance and the coefficient from workplace support and supervisory support to well-being were not significant in the first analyses, no mediation effect could be said to exist. The analyses revealed that the direct path coefficients from workplace

support and supervisory support to work-life balance (.25 and .24 respectively) and from workplace support and supervisory support to well-being (.15 and .22 respectively) were significant ( $p < .01$  for all coefficients). Thus, the analysis met Holmbeck's first step for examining a mediation model.

The second step is to test the partially mediated structural model for both workplace support and supervisory support. In this step, the effects of the direct paths from workplace support and supervisory support to well-being were estimated, and the paths from workplace support and supervisory support to work-schedule flexibility, from work-schedule flexibility to work-life balance, and from work-life balance to well-being were added (see Model A in Figure 3). The results of the partially mediated structural models for both workplace support and supervisory support were very good (e.g., CFI = .96; see Model A in Table 15). In addition, all factor loadings were significant at  $p < .001$ , which indicated that each latent variable was well represented by the observed variables.

Figure 3  
The Partially Mediated Model Between Workplace Policies and the Well-being of Working Parents (Model A)

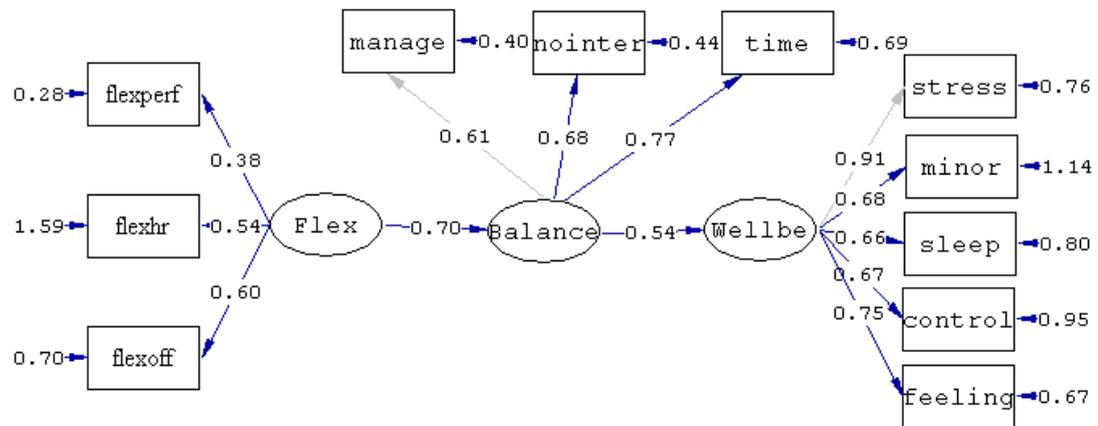


Note. Latent variables: flex = work-schedule flexibility; culture = perceived workplace support; support = perceived supervisory support; balance = work-life balance; wellbe = well-being.

Observed variables: flexper = perfect hour; flexhr = flexible hour; flexoff = flexible off; unwrit = atmosphere; perahead = attitude 1; attitude = attitude 2; jobfirst = priority; favori = favoritism; accommo = accommodation; underst = understanding; cares = cares; manage = balance; nointer = interference; time = enough time; stress = stress; minor = minor health; sleep = sleeping disorder; control = control; feeling = feeling.

In addition, the analyses tested the partially mediated structural model for work-schedule flexibility, which estimated the direct effects from work-schedule flexibility to well-being and added the paths from work-schedule flexibility to work-life balance and work-life balance to well-being (see Model C in Figure 4). The results of the partially mediated structural model for work-schedule flexibility were also very good (e.g., CFI = .96; see Model C in Table 15). In addition, all factor loadings were significant at  $p < .001$ , which indicated each latent variable was well represented by the observed variables.

Figure 4  
The Partially Mediated Model Between Work-Schedule Flexibility and the Well-being of Working Parents (Model C)

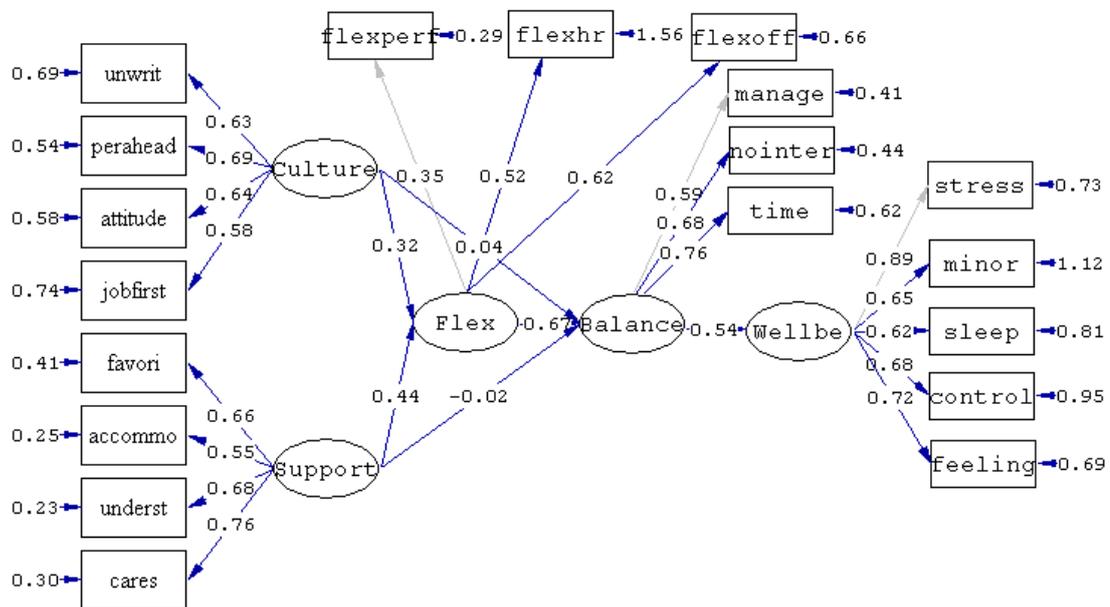


*Note.* Latent variables: flex = work-schedule flexibility; balance = work-life balance; wellbe = well-being.

Observed variables: flexperf = perfect hour; flexhr = flexible hour; flexoff = flexible off; manage = balance; nointer = interference; time = enough time; stress = stress; minor = minor health; sleep = sleeping disorder; control = control; feeling = feeling.

The final step in Holmbeck's (1997) procedure was to compare the partially mediated model (Model A) with the fully mediated model for both workplace support and supervisory support (Model B in Table 15), in which the direct paths from both workplace support and supervisory support to work-life balance were constrained to zero (See Model B Figure 5). The fully mediated model for workplace support and supervisory support provided very good fit indices (e.g., .96; see Model B in Table 15). A comparing of the chi-square difference between the partially (Model A) and the fully (Model B) mediated models,  $\Delta\chi^2(2, N = 980) = 0.57, p < .001$ , revealed that the fully mediated model for workplace support and supervisory support (Model B) was not improved. In short, these results indicated that work-schedule flexibility fully mediated the association between both workplace support and supervisory support, and work-life balance.

Figure 5  
The Fully Mediated Model Between Workplace Policies and the Well-being of Working Parents (Model B)

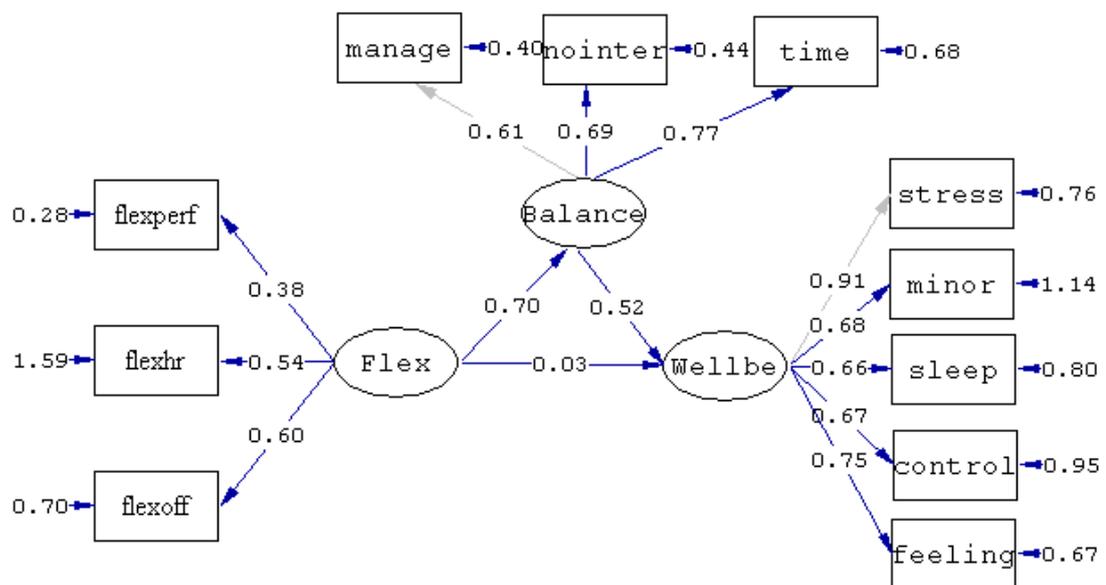


*Note.* Latent variables: flex = work-schedule flexibility; culture = perceived workplace support; support = perceived supervisory support; balance = work-life balance; wellbe = well-being.

Observed variables: flexperf = perfect hour; flexhr = flexible hour; flexoff = flexible off; unwrit = atmosphere; perahead = attitude 1; attitude = attitude 2; jobfirst = priority; favori = favoritism; accommo = accommodation; underst = understanding; cares = cares; manage = balance; nointer = interference; time = enough time; stress = stress; minor = minor health; sleep = sleeping disorder; control = control; feeling = feeling.

Another additional procedure was to compare the partially mediated model (Model C) with the fully mediated model for flexibility (Model D), in which the direct path from work-schedule flexibility to well-being were constrained to zero (See Figure 6). The fully mediated model for work-schedule flexibility provided very good fit indices (e.g., .96; see Model D in Table 15). Upon comparing the chi-square differences, a significant difference between the partially (Model C) and the fully (Model D) mediated models,  $\Delta\chi^2(1, N = 1177) = 0.17, p < .001$ , revealed that the fully mediated model for work-schedule flexibility (Model D) did not improve. These results indicated that work-life balance fully mediated the association between work-schedule flexibility and well-being.

Figure 6  
The Fully Mediated Model Between Work-Schedule Flexibility and the Well-being of Working Parents (Model D)



*Note.* Latent variables: flex = work-schedule flexibility; balance = work-life balance; wellbe = well-being.

Observed variables: flexperf = perfect hour; flexhr = flexible hour; flexoff = flexible off; manage = balance; nointer = interference; time = enough time; stress = stress; minor = minor health; sleep = sleeping disorder; control = control; feeling = feeling.

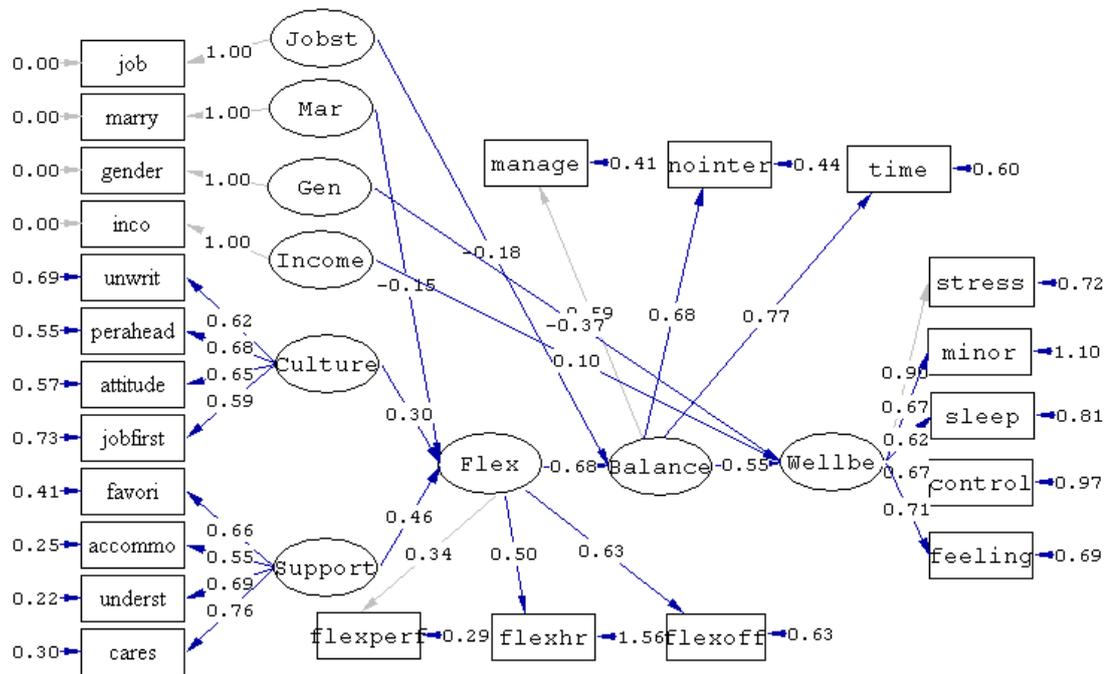
Table 15  
The Mediation Effects

Model	$\chi^2$	<i>df</i>	RMSEA	CI for RMSEA	CFI	SRMR	$\Delta\chi^2(df)$
Model A	376.94*	147	.04	.04-.05	.96	.04	A and B: 0.57(2)
Model B	376.37*	145	.04	.04-.05	.96	.04	
Model C	157.38*	42	.04	.04-.06	.96	.04	C and D: 0.17(1)
Model D	157.21*	41	.05	.04-.06	.96	.04	

*Note:* RMSEA = root mean square error of approximation; CI = confidence interval; CFI = comparative fit index; SRMR = standardized root mean square residual; Model A and Model C = partially mediated for flexibility; Model B and Model D = fully mediated for flexibility

Finally, the full model was tested with four control variables. The goodness-of-fit information for the overall model fit is presented in Table 16. The model is shown in Figure 7.

Figure 7  
SEM Model



*Note.* Latent variables: flex = work-schedule flexibility; culture = perceived workplace support; support = perceived supervisory support; balance = work-life balance; wellbe = well-being. Observed variables: flexperf = perfect hour; flexhr = flexible hour; flexoff = flexible off; unwrit = atmosphere; perahead = attitude 1; attitude = attitude 2; jobfirst = priority; favori = favoritism; accommo = accommodation; underst = understanding; cares = cares; manage = balance; nointer = interference; time = enough time; stress = stress; minor = minor health; sleep = sleeping disorder; control = control; feeling = feeling. Control variables: jobst = job status; mar = marital status; gen = gender; income = household income.

The SEM fit statistics are shown in the model indicated by the equation:  $\chi^2 = 552, p < .001$ . The fit indices for the model shown in Figure 7 are as follows: comparative fit index = .94, adjusted goodness-of-fit index = .94, and root mean square of approximation = .04. These fit statistics indicated that the overall fit of the model was adequate.

Table 16  
Indices for goodness of fit

Model	90% for RMSEA	Standardized RMR	NFI	NNFI	CFI	IFI	GFI	AGFI
Indices	(0.037- 0.045)	0.038	0.91	0.93	0.94	0.94	0.95	0.94

*Note:* RMSEA is root mean square of approximation, RMR is root mean residual, NFI is non-normed fit index, NNFI is non-normed fit index, CFI is comparative fit index, IFI is incremental fit index, GFI is goodness-of-fit index, AGFI is adjusted goodness-of-fit index.

The chi-square model ( $p < .05$ ) was rejected because this significance level means that the given model's covariance structure is significantly different from the observed covariance matrix. Accordingly, because a significant chi square indicates a lack of good model fit, the chi-square value should not be significant. However, the significant chi-square value may be disregarded because of its sensitivity to the sample size. Specifically, the larger the sample size, the more likely the model will be rejected (Type II error); in this situation, the goodness of fit needs to be examined with other fit tests (Hair et al., 1998). The goodness of fit statistics indicated that the overall fit of the model was adequate. All of the paths in the structural model were significant (see Table 13). Specifically, perceived workplace support and perceived supervisory support were directly related to work-schedule flexibility, respectively ( $t = 4.58$ ,  $t = 7.07$ ), which in turn was directly related to work-life balance ( $t = 10.65$ ). Finally, work-life balance was directly related to well-being ( $t = 11.71$ ). As can be seen in Table 17, marital status was negatively related to work-schedule flexibility, indicating that employees who were living with a spouse or partner were less likely to perceive having access to flexible work schedules. This is indirectly supported by previous studies that found that married couples often experienced distress due to multiple role strains (Keene & Quadagno, 2004; Thoits, 1986). In the present

analyses, job status was negatively related to work-life balance, indicating that full-time employees were less likely to report a positive work-life balance. Gender was negatively related to employee well-being, indicating that female employees were less likely to report positive well-being than male employees. Finally, income was positively related to employee well-being. These findings for the three control variables, job status, gender, and income, are consistent with the existing literature (Bond et al., 2005; Heymann et al., 2002).

Table 17  
Direct effects of Construct Variables

From	To	Coefficient	<i>T</i>
Culture	Flexibility	0.30	4.58
Support	Flexibility	0.46	7.07
Flexibility	Balance	0.68	10.65
Balance	Well-being	0.55	11.71
Marital status	Flexibility	-0.15	-3.47
Job status	Balance	-0.18	-2.10
gender	Well-being	-0.37	-5.22
income	Well-being	0.10	2.43

*Note.* If  $|t| > 2.00$ , the path is significant.

*Note.* Latent variables: flexibility = flexible work schedule; culture = perceived workplace support; support = perceived supervisory support; balance = work-life balance; well-being = employee well-being.

These analyses concerned the extent to which perceived work-schedule flexibility and work-life balance mediated the relationship between perceived workplace support, perceived supervisory support, and employee well-being. The results, based on SEM analyses, indicated that perceived supervisory support and perceived workplace support were related to work-schedule flexibility, which in turn was linked to a high level of work-life balance. In addition, a high level of work-life balance was related to a high level of employee well-being.

The mediator model for work-schedule flexibility and work-life balance was found to fit the data adequately and to contain significant path coefficients. As a result, perceived work-schedule flexibility mediated the association between informal workplace policies and work-life balance. Moreover, work-life balance mediated the relationship between work-schedule flexibility and employee well-being. These results expand upon the findings of previous studies and suggest a change in how researchers conceptualize and measure these variables.

## Part II-Qualitative Study

The in-depth interviews gathered information on concepts including work and family policies, leave experience, work-life satisfaction, mood, and emotional well-being and health. Findings from each of these five main categories are presented in separate sections below, which are based on the themes that emerged in the interviews: (a) coping strategies, (b) stress and depression, (c) formal and informal flexible policies, (d) leave experiences, and (e) supportive resources. Before describing the main themes, however, the first section describes parents' initial stressful reactions and coping mechanisms as background information about parents who have a chronically ill or disabled child. The following detailed descriptions will provide information to help understand parents' care responsibilities in extreme situations. In addition, this information gives a sense of the difficulties of working parents who have a child with a chronic condition.

### *The Beginning: The Emotional Stress of Diagnosis*

In this study, parents were asked to report when they first learned that their child had asthma, cystic fibrosis or any other chronic condition, and how they felt at

that time. Almost all parents reported that they experienced complex emotions because they did not know what their child's condition was. About three-quarters of the parents explained that, at first, they experienced severe emotional stress or depression with a lack of sleep from thinking about the child's condition. Over half of the participants reported that they wanted to know everything about their child's condition. Even though parents heard the diagnosis from doctors, they wanted to search for all available information on their own. Cases Q and Z described their initial feelings as follows:

It was devastating and depressing, though, when someone is diagnosed right at birth, it may be easier then later on. You go through it faster. I felt real stressed and was ready to jump out a window. (Case Q)

I wasn't worried about her condition [disabilities] until I started dealing with the school. I didn't know the extent of it. Stress is putting it mildly. I was frantic. I was a maniac. I was driven to find out things, to get her help and I always worry that I am not myself. I am very distracted. I am hyper vigilant for everything, especially when I have to deal with the district or anything with her health. I have nightmares. I have a full charged battery in the morning and then at night I am just done. (Case Z)

As Case Q described above, she experienced shock when she learned about her child's condition. Immediately after most parents learned about their child's condition, one quarter of the parents began to look for more detailed information with expectations of finding new information for treatments or hope for the future. Case J, who has a child with autism, also experienced a very similar process, which included searching for information and dealing with complex emotions like other parents.

Specifically, case J explained:

I went into survival mode when I learned about my son's condition— getting services, finding information —I did what I needed to do. I definitely felt stress but didn't take time to feel the depression. His future is a scary thing and

the stress is still around. I never feel like I am doing as much as I could be doing. (Case J)

One of the most common chronic diseases in children today is cystic fibrosis (Mansour et al., 2000). Three of the four parents who had a child with cystic fibrosis received the child's diagnosis during the first two years after the child's birth. Like many other cases, Case C explained that her child was diagnosed during the first year after birth, and after she learned of her daughter's condition she began to look for information on the disease. Additionally, Case H, a father, also had a daughter with cystic fibrosis. Unlike other children that were diagnosed during the first two years, his daughter was not diagnosed until she was nine years old. We met with him in a waiting lounge of a hospital because his daughter was being hospitalized during the interview. He said:

I was devastated. Our immediate reaction was that she was going to die because my thought was looking back 30 years ago and there were no treatments. My wife told me she would not live after 10 years old. Now, there are treatments. I felt stressed, depressed and there was a lot of sadness. We were given our daughter's diagnosis by a doctor who had a lot of knowledge about the disease and explained to us that there were treatments. (Case H)

However, in the case of parents having a child with a rarely known disease, it was more of a struggle to obtain the correct diagnosis in the beginning. Those parents were likely to feel a strong uncertainty concerning the future. Such uncertainty and ambiguity have been documented as stressors themselves (McCubbin & Patterson, 1983). Case D, who has a daughter that is cognitively underdeveloped, explained the difficulties of how long it took to get the exact diagnosis. Cases O and R had similar experiences as described below:

I was devastated. It took 8 weeks to get all genetic answers. I have gone through every emotion. Why can't my life be like everyone else's, and then I am okay with it. I flip with it. The first 6 months were the toughest because my daughter needed surgery. When she has surgeries, I become more stressful. (Case D)

My daughter's hearing loss and asthma didn't affect me much, but the pulmonary hypertension we worried about because the doctors don't know much about it, and they said my daughter wasn't responding to anything and she would die young. Everything was out of control at about 4-5 years old. When someone tells you your child is going to die young, there is grieving. (Case O)

It was overwhelming to get the right services; I was scrambling to get what he needed and finding out how to do that. Early intervention was supposed to start when he was 2 years old, though there was no therapist available and he had to wait for 4 months. He was eligible for 2 hours a week and they only gave me one; he also didn't have a diagnosis and we went to four different doctors to figure out what was wrong. (Case R)

Similar to Cases D, O, and R, parents who had a child with a rarely known disease described how many hospitals they had visited to get an accurate diagnosis and how far they often traveled to visit doctors. Case O explained that she quit a very good job to move near an available hospital for her daughter.

As described above, the majority of parents reported that their reactions included shock, fear, and stress, among others. On the other hand, a few parents explained that they were rather relieved after a diagnosis because they had worried so much about their child prior to the diagnosis, understanding that something was wrong with their child but not knowing exactly what. Case M, who has a child with ADHD and asthma, and Case N, who has a child with Asperger's syndrome shared their reactions to finally receiving a diagnosis:

I was so happy because I didn't know what was wrong with her and then there was a diagnosis; my daughter was really crazy: jumping off tables, attention deficit. (Case M)

I felt very relieved because I kept telling myself that something wasn't right. Now, I have something to work with now, and I can figure out something to do. Basically, I learned everything I could about the condition and was able to get a very good neurologist. (Case N)

As Patterson (2002) points out, events such as the diagnosis of a child's chronic health condition is a major stressor for the family: it might prompt anxiety, depression, and stress. Case G has a daughter with multiple handicaps, who has had her conditions since birth. When she heard that her daughter would face an early death, she expressed how she felt as follows:

Everything was unclear. It was difficult because no one could explain to me what was going on with my daughter. The doctors got a book and read to me about her conditions and told me she was going to die. This caused emotional stress. I also had a child who passed away from cancer. (Case G)

As the majority of parents reported, they experienced anxiety and uncertainty due to their child's condition as well as apprehension about the future after retirement or upon aging. Case B, who called herself a weepy person, had been on antidepressants ever since her child was initially diagnosed with cystic fibrosis. Case K and Case W also had many concerns about what was going to happen in the future regarding the care of their children.

It began as anxiety when I learned about my son's condition as a baby. I began to have panic attacks. I went into therapy, learned about depression, and that I had it. (Case B)

The first year was easier because I did so much reading, and the second year I realized it was something I will have to deal with the rest of my life. He will be probably living with us for the rest of our lives. We had to make a will, and found out that my mother and sister-in-law wouldn't be able to take him, and my sister wouldn't either. The only family was an aunt that would take them. What will happen when we retire? The second year started my depression and I started seeing a psychologist and he put me on Wellbutrin. (Case K)

One of the big worries of parents with kids that have significant disabilities is what is going to happen to their future, so we feel that we should have a trust fund set up for her to that who ever is caring for her, there is money to do it. (Case W)

In our study, two parents had more than one child with a chronic condition, while ten parents had a child with multiple chronic conditions. Case I has a son and a daughter with cystic fibrosis, and the daughter has diabetes as a result of the cystic fibrosis. Case E has a daughter with multiple chronic conditions including kidney disease and autism. These parents explained their feelings about these extreme difficulties as follows:

First one was a shock. I wondered how my daughter got it. When my daughter was diagnosed she wasn't sick; my son was diagnosed 15 months after my daughter was diagnosed in 2001. Until two months ago I was in rut because my daughter's condition wasn't good and it was tough. (Case I)

When she was born, I had a feeling of extreme unfairness because I was very careful during the pregnancy. The second time with the autism was more devastating to me because I thought of quality of life. I did not do what everyone else did. The first 10 months my daughter was here I made phone calls on everything to see what I was dealing with. (Case E)

Almost all parents reported that they experienced lack of sleep, anxiety, stress, and depression after they learned of their child's condition. In fact, several parents were crying during the interview. One of the parents mentioned that emotions such as sadness never ended even though there was some degree of difference over time. For some parents, however, their child's condition was chronic but not as serious. Case P, who has a child with mild asthma, said:

It didn't affect me much because it runs in my family and I figured someone would get it. We know how to deal with it and my husband also has it. Someone had to stay overnight with him when he was a baby. I knew he was going to have asthma because he was breathing heavy. (Case P)

As described by these respondents, once the family confronts the situation, they eventually realize that it is not temporary, but it will last for life. Thus, parents have to adjust their work and life schedules to take care of their chronically ill or disabled child.

### *Stress and Depression: Chronic Condition and Responsibilities*

As family stress theorists point out, an event such as receiving the diagnosis of a child's disabling condition is a significant stressor for the family (Patterson, 2002). Many parents that have a child with a chronic condition or a disabled child may have mental health issues such as stress and depression. It is unknown how they handle their emotions at work and home.

One of the most difficult aspects of having a child with a chronic condition is the need to care or monitor the child consistently throughout one's life. Respondents were asked to describe how they took care of their child on a daily basis, and what coping strategies they employed in managing family life and the home environment. From their comments, it appeared that some of the children attended a school or day care program at which personnel provided services for children with special needs. Many parents described a routine that required extensive monitoring and accommodation for their children whether they were at school, day care, or home. For example, Case B has a son with cystic fibrosis. According to her description, her son took as many as 15 medications a day, including some in the form of pills, liquids, and inhalers. The medications were taken at all hours of the day, and, accordingly,

there were morning- and middle-of-the-day routines. Some pills were taken twice a day, three times a day, or at every meal. Therefore, she had to try to organize her daily life to be aware of the time and know what was to be done at all times. She also had to do percussion to clap the mucous out of him in 12 different places, which she did for 40 minutes a day. In addition to managing daily tasks related to the condition, she also had to do many other things such as visiting the doctor, preparing healthy meals, shopping, and attending school-related needs for her son. On top of all of this, she also worked part time. Similarly, Case C, who has a child with cystic fibrosis, reported that her daughter took 8 medications orally every day plus a nebulizer 2-3 times a day. Case I has both a son and a daughter with cystic fibrosis. Her daughter, who has cystic fibrosis and Type 1 diabetes, takes about 80 pills every day with food. Case I expressed that she was in constant communication with her children's school because she wanted to monitor her child's condition while her child was at school, like many other parents that have a child with a chronic condition.

As described above, almost all parents needed to pay attention to their child continually to manage medications on a daily basis and to monitor their child's daily tasks. Parents that had a younger child with a chronic condition had even more responsibilities regarding the care of their child and the condition. Several children were not able to take care of themselves at all because they were too young or the condition was very serious, so the parents had to monitor them constantly. In Case A, the mother expressed how her daughter needed to be carried everywhere in the house and could not be left alone. Cases W and Z, who have children with a disability, explained their children's need for constant care as follows:

She is almost 16 and she can speak in maybe 3 word sentences, she doesn't know her letters or numbers. She can go to the bathroom on her own but she

needs help showering and getting dressed, so daily life activities. She needs 24-hour supervision. She needs to be with someone all the time, not in the room with her, but somebody needs to be close by. (Case W)

I have to get her up and get her breakfast and then shower and dress her every day. Some day she is more cooperative than others, but she usually comes around. I have to make time in my morning, my husband helps me so with that, but as she has gotten older, it is not as appropriate to have him shower her, so that has fallen on me. (Case W)

I wake up in the morning and as soon as my daughter is up there is some issue. If she is up then everyone has to be up and she has to eat right away. My day with my daughter is like there is always something to deal with. I have to try and teach her household rules. She has a weight problem as well, and it becomes an issue when she can't have something to eat. Getting out the door is an issue, and then picking her up from school depending on her school day is an issue as well. Her mood will deteriorate when something doesn't go her way. It is always something to deal with. (Case Z)

Some parents that have a child with a disability such as autism have several kinds of therapies. For example, Case D, who has a child with underdeveloped cognition, explained that her daughter received five therapies a week, including two occupational therapies, two speech therapies, and one developmental intervention. Case J's child, who has autism, received two therapies a week in school. Case E has a fourteen-year-old child with multiple chronic conditions including kidney disease and autism, and elaborated on her child's care and therapy as follows:

We make all food and any time we send her somewhere we have to make all her food. She can't have fluoride: no fluoride toothpaste and no aluminum. She takes medications for her kidney disease. Everything is given at home. She also has special toileting hygiene. She has ADD and ADHD, so she loses her focus. We have visual stuff and schedules throughout the house with visuals on how to do certain stuff. We supervise everything. I lay out her clothes a certain way. She has a sleeping disorder from autism. She does therapies at home to reinforce what she does at school, like speech therapy and sensory integration. Everything is baby proof at home because she falls a lot and without supervision she can't eat or drink herself; we have to tell her to use napkin or fork. (Case E)

The majority of parents in our study have a great number of things they need to do to manage their child's condition, such as taking care of nutritional needs, arranging and taking the child to therapist's and/or doctors' visits, and performing any number of other care-related activities. Slightly more than half of the parents in the present sample needed to communicate constantly with their child's school. Because parents had to manage so much, they typically started their day around 5:00 a.m. and ended late. Most parents reported that they usually had planned schedules for each day so they would not forget anything important. During the interview, a couple of parents brought their time schedules to illustrate its complexity. All parents, with few exceptions, had adjusted their work schedule for their child. Case G said that her daughter, who has a disability, went to school throughout the year and had some breaks. Her husband worked mornings and she worked afternoons, so that one of them was always there for their daughter.

The majority of parents reported that they had experienced some degree of stress and depression in the process of adapting their work and family lives since the diagnosis of their child's chronic health condition. Patterson (2002) identified several coping strategies to deal with stressors, emphasizing family stability and balance in the process of adapting to major, non-normative stressors such as the diagnosis of a child's chronic health condition. In our study, over half of the parents reported how they had to struggle to mold their life into a "normal life," maintaining the mindset that their family and child were not "abnormal," just "different." For instance, parents were likely to keep their situation as low key as possible in order that others would see them as having a "normal" life. Also, they expressed how much stress they had felt in the process of trying to create and maintain this sense of normalcy." The next

section will show how parents' adjusted to working and caring for their child with a chronic condition or disability.

### *Work, Life, and Adjustment*

Half of the respondents reported that they had to have a part-time job with flexible hours because they needed to monitor their child's condition. Parents who had few resources available in their workplace reported having more difficulties in coping with their family situation than those with greater benefits and a higher income. Parents who have a child with a chronic condition may have greater financial needs than parents without such children due to increased medical costs, so they need more benefits. However, half of the parents in the present sample had taken part-time jobs with relatively fewer benefits because it was easier for them to manage their child's care with a more flexible work schedule. However, most of the respondents in our sample were married, so they were able to draw on their spouse's benefits. Cases G, F, and Y, who all had part-time jobs, explained how they had handled childcare.

I am part time and my schedule is very flexible. Since my daughter is off of school this week, I will go to work in the afternoon. My husband has to take vacation leave from his job but it is only half of his vacation time. (Case G)

I am only part time so I haven't run into a problem with going to doctor's appointments. (Case F)

I left the position I was in the past fall because my son was having a lot of problems and at that time I was working full time. I changed my hours because of my kid. It came to difficult. My husband was working like 80 hours a week and I was working a 40 hour week and it was getting out of control. Now I can schedule things a lot more easy. (Case Y)

Case A, Case D, and Case L reported that their partner either had quit her or his job or had switched to a more flexible. Sallfors and Hallberg (2003), who explored

the perspectives of parents with a chronically ill child, pointed out that parents who have a child with a chronic condition need to continually adjust to manage their daily lives. Many of the respondents in our study also reported having to adjust and readjust their work and family lives. Robinson (1993) explained that managing work-life demands through a balancing act between husband and wife is one of married couples' coping strategies to construct "life as normal." Cases A and D described their efforts in this respect as follows:

My husband doesn't work; he stays home with my daughter full time. He finished a degree in primary school education. His sister came to live with us so he could finish his degree. (Case A)

My husband has a very flexible supervisor. He never had to take a sick day or family leave for any day he needed to take off for our daughter. He has a personal relationship with his boss and it is extremely workable. He is traveling more now on 3-week cycles, and [my husband] now needs more training [at his work]. (Case D)

Case D mentioned that her husband needed to travel more for his job.

However, she explained that he was still available to share the responsibilities for their daughter because her husband had good relationship with his boss.

About three quarters of parents had changed their work schedules so that their schedules coincided with their children's school day or had looked for jobs that had more flexibility. For instance, Case Q said, "I have never changed my work schedule; I have always looked for jobs that weren't as demanding." Case W and Case Z explained their experiences regarding job adjustment. Case J, who had changed her work schedule so that it fit with her child's school schedule, also reported on this process.

I wasn't working when my daughter was younger and she was having behavioral issues at school and the school was always calling me, so it was good that I was home because if I was working at that time, it would have been difficult for me. (Case W)

Since my daughter was one year old I have never worked at a job as an employee. I have always gotten a job where I could have a flexible schedule. When I worked at the elder care agency I arranged my schedule how I wanted. (Case Z)

I went part time, then went to 4 days a week when he went back to school. Prior to going to school he was with a babysitter, and when my daughter got older, I went back full time. I wouldn't consider working for a job other than a school system because I have the same days off that my kids do. (Case J)

Unlike the two parents in the families described above, the single working parents in the sample had more difficulties arranging work and family responsibilities to meet the burdens of caring for their child physically, emotionally, and financially. Two single mothers, Cases B and C, who have children with cystic fibrosis, explained that they had to get a job that had flexibility: there was no choice.

I used to be an employee for American Airlines but when my son was born I had to give up that job. I went into hair styling because I knew this occupation offers flexibility: If I need to take a week off to be with my son, I can do it. (Case B)

Before I divorced and had a sick child, I didn't work during the week and worked on weekends. Then, I was able to take care of her a lot better and now it is more difficult because time is limited. (Case C)

Many respondents said that caring for a child with a chronic condition was like a full-time job. Because of the burden of caring for such children, solutions at the family level have limitations, especially for working parents. Family stress theorists agree that stressors may be mediated by personal, family, and community resources (McCubbin & McCubbin, 1991; McCubbin, et al., 1995; McCubbin & Patterson,

1983; Patterson, 1988; Patterson, 2002). In particular, as shown in the results of the quantitative study, resources such as work-schedule flexibility are related to stress solutions. However, family stress theorists often disregard the importance of resources in the workplace and the level of employment in successful family functioning. For example, parents who have a child with a chronic condition often need paid work that is guaranteed to have great flexibility. If parents are unable to get a paid job with flexibility, then they can only participate in the workforce when other helpers or caregivers are available. Parents who have a child with a chronic condition typically need to use time off, often for a doctor's visit or an emergency call. Because of such reasons, resources such as formal flexible policies with job security at work are very important for them.

### *Resources*

#### *Resources at Work*

##### *Formal and informal flexible policies*

Almost all parents interviewed for this study reported that work-schedule flexibility was beneficial for them and allowed them to manage work demands and care for their children. According to the respondents, parents who had the flexibility to make their own hours were likely to feel comfortable making changes in their work hours to accommodate childcare needs. However, when work-schedule flexibility was not guaranteed through formal company policies, most parents reported that they experienced stress when changing their schedules. The following statements discuss examples of how the stress or fear that these parents felt because of what they assumed that their employers and co-workers would think about their absences.

The stress of working with kids is difficult, but the stress of working with a child with a chronic condition is more difficult. Her doctor's appointments are during the day and I have to leave work and take her out of school. (Case Z)

Stress is due to the fact that if someone is late, the assumption is they have taken the child to the hospital. (Case A)

Case D is an adjunct instructor in a college who explained how she felt when she missed a class to provide urgent care for her child with a chronic condition.

There is a lot of stress and guilt when I miss a class. I missed a college day and felt guilt and stress because I missed a day where I could have taught my students for finals that they needed to take. (Case D)

Because of such stress and guilt, many respondents tried to find a new job that permitted greater flexibility, efforts that some researchers have also found when examining the relationship between turnover ratios and leave policy (Milkman & Appelbaum, 2004; Orfalea, 2004). Case C stated that she did not like her current job, but she liked the flexibility; specifically, the formal access to a flexible work schedule made it possible for her to manage her work demands and the care for her daughter with cystic fibrosis. Even though some of the respondents had lost good health, pension, and/or vacation benefits in leaving their previous job, they reported that they preferred a job with time flexibility. In another example, Case B, who is a single mother and had a job as an administrative assistant with great benefits, gave that job up and trained to be a hair stylist, which is a job with few benefits. She explained that the formal flexible work schedule that her hair stylist position offered her made it possible for her to manage work and care for her son with cystic fibrosis.

According to Heck and Makuc (2000), single parents with special-needs children are more likely to be mothers. In this study, there were four single mothers of

children with special health care needs. All of these single mothers reported that they preferred a job with time flexibility so that they could care for their child. At the same time, they explained that they had difficulties utilizing work-schedule flexibility because, although it allowed them to take time off of work, they were not paid for that time. Both Case B and Case C are single mothers, and they described the stress they experienced with unpaid time off as follows:

Despite the flexibility, I experience stress. The clinic visits will be increasing and it is difficult to take off too much time because if I take time off from work to be with my son, for example if he is in the hospital, I can do it, but I don't get paid. Or, if I need to take a week off to be with my son, I can still do it, but if I miss work, I don't get paid. And if I am out too often, I lose my clients. (Case B)

I can take time off, though I don't get paid when I take time off. I am able to take a week off; I just won't get paid, so I don't take time off work. (Case C)

Case C described her difficulties with unpaid time off with the words, "if I miss work, I don't get paid." Another single mother (Case M) who has a child with asthma, explained that she has always had the ability to stretch a dollar but has had to struggle. Case M's experience is similar to that of other single mothers in that she has positive feelings about her job because of the availability of formal flexible policies. Specifically, Case M is a mother who works as an emergency housing dispatcher for the University housing department that must answer any emergency for 24 hours a day. Even though her job does not offer time flexibility because of the nature of the work, she explained that she likes her job because it pays enough to cover her living costs and offers her "place flexibility," meaning that she can work at home or any other place.

Access to a formal flexible work schedule is important to parents of children with chronic conditions, although most are unable to use unpaid leave even when it is available as will be described in next section. Another important resource at work is leave policy. The following section gives information about the leave experiences of the respondents in this study sample.

### *Leave experiences*

Formal leave policies are important to parents who have a child with a chronic condition because such policies make it easier for parents to find a balance between work and family responsibilities and to take time off from work to take care of needs relating to their child's condition. As mentioned previously, even though the US has the FMLA in place, this policy has limitations because the leave is unpaid and can only be used when the workplace has 50 or more employees. Indeed, among the parents we interviewed (as noted in Table 6), there were only five who had taken family leave using the FMLA. In addition, New Jersey has its own family leave act, the NJFLA, which provides employees in larger firms with additional leave opportunities, but as with the FMLA, this legislation does not provide income replacement. Case H, who worked for the government as a lawyer, explained his leave experience as follows:

When it (FMLA) first came out, I used it regularly for my daughter. I feel that it gives the employee a little more control when they need to take off. It is a law that gives them the right to do that. Without that law, then it is up to the employer to either be nice or not. (Case H)

Case H, however, mentioned that he never had financial problems with unpaid leave, so it was easier for him to use the leave. Another respondent, Case N, who is an

applications specialist and works for a law firm, also had a leave experience, which she described as follows:

I have taken an [intermittent] unpaid leave [as needed] for 4 years. I found out about it from another mom with an autistic child, but I thought it was only taking days and then I found that I could take hours. Financially, we make what we earn; I am working 35 hours plus I am on call for 26 weeks out of the year, and when I dropped back my hours, they adjusted, and when I dropped back again, they adjusted; if they have problems, they deal with them. (Case N)

Case U explained that 52% of her time has to be spent performing home visits as a registered nurse, and she only receives 12 weeks of unpaid family leave. She explained the pressure to meet both work and family demands as follows:

They are flexible for that 12 weeks but they always mention that it is for the 12 weeks. It is business, so I understand. As flexible as it is, it is still stressful because I still have to meet my quota and I only get 12 weeks of unpaid family leave and its like how many weeks have I used, its only December. (Case U)

Few parents in the present sample could afford to use FMLA leave. Instead, the majority of parents had to find ways to continue to juggle work and family. Case J, the mother who has an autistic son, stated that when her son was diagnosed, she cut back her work hours. Similarly, Case A explained that her husband quit his job because one of them had to care for their daughter.

She needs to be carried everywhere in the house. She doesn't have much function in her hands. It takes a long time for her to feed herself; breakfast takes an hour. She is in a disabled pre-school class in the public school. Her father picks her up. She has lunch, then naps, has some therapy, then dinner, and then bed at 7:00 p.m. She is not yet toilet trained. (Case A)

Even though many working parents had already adjusted their employment situation to care for their chronically ill or disabled child, many still had additional problems. They needed a work schedule with flexibility, specifically a schedule that coincided with their children's schedule, because they had to supply constant supervision of their child's behaviors and daily tasks. For example, Case G had a part-time job with a flexible schedule, so she was able to adjust her job to meet the demands of caring for her multiply-handicapped daughter, who needs assistance with essentially all tasks and activities. She stated that, "Since my daughter is off of school this week [because of summer vacation], I will go to work in the afternoon. My husband has to take vacation leave from his schedule." As with Case G, many parents with a child who needs constant supervision had changed their schedule in some way, and they had usually looked for a job that had a formal policy permitting a flexible work schedule. Case Y also reported that her son was absent 11 times during the school year, and she used sick days or vacation time during that time, but it was all unpaid leave.

#### *Caring and Support: Caregivers*

Parents' abilities to cope with the stress created by their child's situation were related to having supportive resources at the personal, family, community levels. There are few formal supplemental caregivers for parents of chronically ill children coping with work-life balance, so many such parents report that they often experience a lack of support (Robinson, 1993). Most respondents in the present sample reported that they had managed these demands by themselves without the help of other caregivers. However, slightly more than one third of the parents interviewed for this study had close relatives such as grandmothers or friends who they were able to rely

on for childcare assistance. For example, Case A reported that she lived with her mother during the winter months. Case C reported that her parents lived close by her. Case F said, “My sister or aunt takes care of my children sometimes.” Like other respondents, Case G described the reason that she preferred to receive childcare help from her family members instead of an agency or a babysitter.

My sister-in-law takes my daughter to the bus stop once a month. My parents are coming up to take care of my daughter. Parents are not close by, but if given enough time, they can come and help us. We were looking for a babysitter, but I don't know if I would be comfortable. I tried a nursing agency, but they were very unreliable. (Case G)

Generally, parents of children with a chronic physical illness or disability have more worries when somebody watches their children. In the interviews, some respondents reported relying on neighbors or their friends when they need help for a short time. Case H, Case I, Case Z reported that friends sometimes lent a hand.

I have friends that would like to help out, but when it comes to my daughter's health care, I wouldn't feel comfortable asking for their help. My daughter's half sister would help out my daughter. (Case H)

Friends here and there, for example, if my daughter needs to go to doctor, my son will go to a friend's house. Also, my daughter's friends know about her illness so they watch out for her as well: close friends more so than relatives. (Case I)

I have a friend who is like my sister who will help. I have a really good network of friends here in NJ with picking them up from school, but as far as relieving me with some of the responsibilities of my daughter, they can't do it. (Case Z)

Of course, some of the respondents had a babysitter, but most of the respondents relied on help from close relatives. As previous studies have pointed out, support from friends or relatives were one of the coping strategies often utilized by

parents of chronically ill children (Sallfors & Hallberg, 2003). In this study, the primary helpful caregivers were women such as the respondents' mother, sister, or aunt. However, the interviews revealed that many parents also had problems in relying on family members for help. Case D, who had received help from her mother, sister, and immediate family, explained that she felt bad when asking her mother to watch her child.

Respondents who did not have close family members who were able to help them had more difficulties managing the multiple demands of parenthood and employment. Therefore, a social support network in communities may be important for parents of children with a chronic condition. Family stress theorists commonly claim that if a family has adaptive resources including "existing" resources (e.g., work and the ability to manage their child's needs) and "expanded" family resources (e.g., other caregivers including the child's grandparents and relatives), that they may be better able to meet their care responsibilities (Hill, 1958; McCubbin & McCubbin, 1991; McCubbin, et al., 1995; McCubbin & Patterson, 1983; Patterson, 1988; Patterson, 2002).

### *Stress, Support, and Resources*

#### *Stress, Depression, and Management*

There are many potential stressors for a family that has a child with a chronic condition. These include anxiety as the result of an unexpected health episode, financial concerns, and social stigma related to the child's condition. In addition, the respondents in the present study reported that they often experienced certain kinds of stressful interruptions at work. Case N and Case E, who had children with ADHD and autism, respectively, explained this situation as follows:

I have to keep my cell phone on my desk at work, and if it rings my heart stops because I think it is something bad. (Case N)

I have physical fatigue more than mental: no time to take care of my self. If I get upset my daughter will freak out because she is autistic, so I can't show emotions in front of her; I try not to let it affect my daughter or work. If something happens to my daughter that is my weak spot. (Case E)

As discussed earlier, some parents who did not have formal flexible policies reported experiencing stress when they needed to take time off. Case L and Case Z described examples of the best and worst work scenarios:

The worst is saying that I need time off and my co-workers groaning and making me feel guilty to request time off. (Case L)

The best is when I worked with someone who understands that things come up and trusts that when things come up, you will do what you are supposed to do, but understands that this it is only a job and your children always come first. The worst is when you are made to feel guilty that you can't be there, that is constantly putting you in a position that you have to explain yourself. (Case Z)

Case B, who is a single mother that has a child with cystic fibrosis, explained that she had to work without any breaks to maximize her earnings. However, she sometimes needed to take time off for her son. She explained that she felt stress when she lost clients because of this. Case B and Case J also mentioned that their financial situations were very stressful.

A couple of parents indicated that they became stressed because of the stereotypes regarding their child's disease. Case K, who has a son with Asperger's syndrome and ADHD, began to cry during the interview while she reported some of her negative experiences.

So much has been so unfair. The whole incident of being kicked out of school and so many experiences that have been bad; the teacher was responsible. If I was working full time, I would have never gotten my foot in the door. (Case K)

It affected me terribly because I felt that I lost a child. I always thought he had Down syndrome [child was diagnosed with Down syndrome when he was born. He also has seizure disorder and mild asthma]; my husband was fine and optimistic. [At that time] I went back to work at 4 weeks because I had a very busy job. It took me at least 9 months to a year to get past everything. (Case L)

In our study, parents reported a variety of strategies to solve their depression or feelings of stress. Four parents attended support groups to share their experiences. A couple of parents said that “there is no time to get to a support group because they have been busy.” And, some other parents reported using strategies such as reading a book, meditating, exercising, or drinking a little.

A good cocktail alleviates the stress. Reading a book or taking a hot bath also helps a lot. (Case A)

I stopped taking drugs and started doing something new for myself which helped me alleviate stress. I also learned how not to stress. Other things I do to alleviate stress is to read the bible, attend bible study and prayer. I also channel my energy onto someone else, mediation, and reading. (Case F)

Tried yoga and gym; commitment for myself is tough because of work; tried a once a month dinner with friends, but never happens. I can't do anything for myself. I e-mail a lot and friends come over now and hang out and play cards. (Case D)

As described below, Case B and Case I had taken anti-depressants and other drugs.

I have been on anti-depressants and that has helped me maintain my positive attitude. I am a weepy person. I usually want to be alone, but praying, exercise, talking to a friend is helpful to me. In the workplace, many of my

clients have been with me for years. They ask about my situation, and ask me lots of questions, which feels like therapy to me. I feel so much better at the end. I am glad that talking is in my job description. (Case B)

Case I expressed that “Drugs only help me alleviate stress.” Case G said that “sometimes I allowed myself to be down if I had time.” Unexpectedly, many parents reported that they liked to try to focus on their tasks at work, which gave them relief from thinking about family demands or stress.

The demands of everyday life do not affect my work, but it affects home. Yelling helps me alleviate stress and the demands of everyday life. Also, I try to keep things in perspective and try to make the best of it. I blow up at work, but it is not as vocal. I will tell whatever it is that is bothering me, but also try to maintain some equilibrium at work. The pressure of my daughter’s condition causes stress in the home. There are things that didn’t use to get to me, that now seem to bother me. (Case H)

So busy so I don’t have time to sit and think about the demands; not enough time in the day to think about everything. (Case C)

Most parents relied on solving their depression or stress individually. Research suggests that it may be important for family members to find various resources to help them cope because stressors and resources, including informal and formal social supports, are related to a positive quality of life (Patterson, 2002).

### *Support group*

As mentioned above, family and friends may provide social support. In addition, support groups may affect well-being. In this study, there were four people who attended a support group in which they communicated with others, sharing similar experiences and helping each other manage common problems. As many previous studies have found, support groups can be beneficial in that parents share

common experiences and information about care (Bennett & DeLuca, 1996; Huws, Jones, & Ingledew, 2001). Case E and Case J explained that their support groups helped lower stress levels. Case X reported that he obtained useful information through online support groups at the beginning when his child was diagnosed with allergies. Case J reported that she helped to start a support group in her township. She and two other parents have continued to help the support group grow. According to her, there are 75 families in her group, which has been developing for 5 months. They have had 5 meetings in which 20-30 parents managed to attend. Parents do this for emotional support, for networking, and for finding out information about issues such as schools and care tactics that other parents have tried. However, a couple of respondents said, "I do not have time for support groups." In a study to examine why parents often do not attend support groups, Smith, Gabard, Dale, and Drucker (1994) found that parents often had a lack of available time. Others do not find the experience beneficial. In the present study, Case N elaborated on her feelings about a support group that she had been involved in but eventually left.

Everyone sits there and complains and I think it is unhealthy, though it makes other people feel they are not alone. Only when there are guest speakers, then I will go. (Case N)

#### *Financial resources*

About half of the parents had received financial support from various sources for their child. Case R, who has a child with autism, Case D, who has a child with cognitive developmental issues, and Case W, who has a child with developmental disabilities, had had received some funds from the New Jersey Division of Developmental Disabilities (DDD). DDD is a service that is available for individuals who meet the definition of a developmental disability such as mental retardation,

cerebral palsy, epilepsy, autism, or other neurological condition. Case R explained that her family received respite care funds through DDD. Case D reported that, despite receiving some funds through DDD, her family's financial situation was not good because the costs for doctor and therapist visits were not covered by their insurance. Case T, who has a child with autism with Pervasive Developmental Disorder in Mentally Retarded Persons, had received some money from DDD, but she expressed that it was not enough to cover her child's medical costs. Case T described their financial situation as follows:

Financially 5 years ago, we were better because we weren't doing treatments that we are now. Our medical insurance doesn't cover it, though; we do receive some money from DDD, which is a little support. (Case T)

Some parents are eligible for financial assistance from other sources such as Medicaid or Social Security Disability and Supplemental Security Income. A study that examined the use of specialists by Medicaid-enrolled children from California, Georgia, Michigan, and Tennessee (Kuhlthau, Ferris, Beal, Gortmaker, & Ferrin, 2007) found that most children with a chronic condition, other than asthma, received Medicaid. In the present study, Case S and Case F received a little support from Supplemental Security Income (SSI). Case S explained that her family's financial condition was not that bad because her child's condition was covered by insurance and her daughter's condition did not require a great deal of medical costs. However, when her daughter turns 18 years old, the family's financial situation may change because the eligibility requirements for SSI are different for adults. Thus, the family's future financial situation is not stable. Case S, Case F, and Case W explained their financial situation and concerns about the future as follows:

Her condition doesn't require a lot of medicine and through employers there is insurance. The money for her medical condition isn't bad; we are ok. There are no other services after she turns 18. She gets Supplemental Security Income (SSI) which is \$400 a month and she is a junior counselor at the YMCA and earns \$50 a day. (Case S)

My daughter and I are on SSI. I am trying to reach out to a couple of churches to help me get back on track. I make about \$120 a week. (Case F)

One of the concerns we are starting to have financially is saving for retirement...DDD, depending upon how much funding they are getting, they have services transitioning people into the adult world, so they have day programs to make sure my daughter has something to do. She should qualify for SSI so that will be a cash input. (Case W)

Many respondents, however, did not receive any external support because of program eligibility requirements or for other reasons. Most parents reported that they had to spend great amounts of money each month because of situations not covered by their insurance. For example, Case I and Case V said:

We meet a \$5,000 loan each month; get some help from pharmaceutical company with health insurance; a lot of out of pocket expenses and any extra stuff that insurance doesn't cover. (Case I)

We had to pay for the formula which was \$1,200 a month and then insurance stopped paying for it. (Case V)

Case Q had an experience with quitting her job because her employer was not willing to pay the medical costs, explaining:

For a while I was working in a day care; I have had several different jobs. People don't want to deal with the amount of added cost to their medical insurance so that is why I have lost several jobs. Eight years ago, I found my current job. The reason was never my choice for leaving my other jobs; it was because of all the time taken away from the job and the demands of care and impact of insurance. (Case Q)

Like Case Q, many other parents who have a child with a chronic condition faced unstable circumstances in terms of their child's condition, the family's financial status, and their job security. In particular, parents who lacked financial resources experienced severe and continuing stress. For instance, Case C said, "I can't work enough hours to pay bills." Case G also received a little support through DDD, but she explained that she had to keep working and had difficulties covering expenses. She stated:

I have always worked whatever schedule worked for me: worked weekends and evenings. I am registered through DDD and there is a little bit of money for some activities. (Case G)

Single-earner parents in two-parent families or single parents are more likely to experience financial issues than dual-earner families in two-parent families. Case Q, a single-earner parent, described her situation as follows:

Financially, we are tightly managing it. It has been ok; my husband couldn't work for a long time so it has been difficult. We have no other resources; I just kept working. (Case Q)

Case B, who is a single mother, expressed the difficulties she had in managing financially. In addition, she pointed out how complex it was to deal with Medicaid as follows:

Now I am divorced, and it is hard for me to manage. My expenses increase due to inflation and as my son gets older, he has other needs as a teenager, but my child support payment is fixed. My son's medicines cost \$5,000 a month, sometimes \$8,000. He is on Medicaid, but this is very time-consuming to deal with; Medicaid has thrown him off [the Medicaid rolls] several times. (Case B)

In the present study, there was one parent who had received significant financial support from her community.

Thirty neighbors threw a fundraiser for my daughter for horseback riding therapy which was called the Hunterton County Fundraiser. Plus, we applied for the NJ catastrophic children's fund which has 2 elements: 1<sup>st</sup> element—spend more than 10% of gross income on disability, they refund it; 2<sup>nd</sup> element—transportation, \$70,000 for a car plus lift. (Case A)

As described above, other respondents of our qualitative study had received a very small amount of money from public support. In addition, their health insurance did not cover all of their medical care costs. These limited financial conditions made these families' situations worse. Because of this, the community-based support that was available to Case A was important in helping her manage her family.

## CHAPTER 5: DISCUSSION

This chapter discusses the findings of the quantitative and qualitative studies. Implications for theory, policy, and practice are addressed, and limitations and recommendations for future research are discussed.

### *The NSCW Data*

Research questions 1 through 8 and their corresponding hypotheses were answered using the quantitative NSCW data set.

#### *Perceptions of Workplace Policies and Work-life Balance*

The first two research questions examined whether employee well-being was related to perceived workplace support, perceived supervisory support, and perceived work schedules. The corresponding hypotheses stated that working parents who perceived a more supportive culture in the workplace would be more likely to report greater flexibility; and working parents who reported higher levels of perceived supervisory support in the workplace would be more likely to report having access to greater workplace flexibility than working parents reporting lower levels of perceived supervisory support.

This study found that perceptions of a positive organizational culture and supervisory support had particularly strong associations with an individual's perception of their access to a flexible work schedule. This study confirms the findings of some previous studies and offers several new findings as well.

First, previous studies have measured workplace flexibility with a single variable such as work-schedule flexibility, compressed work (e.g, being expected to complete a large amount of work in a small amount of time), time-off, parental leave, or reduced hours, without taking into account other variables that might mediate the relationships between the main variables. In contrast, the present quantitative analyses were able to capture the flexibility of work schedules more accurately by utilizing a latent variable including three measures and an important mediating variable. Utilizing multiple regression analyses, most previous studies have found positive correlations between workplace flexibility and turnover, absenteeism, or job satisfaction (Dalton & Mesch, 1990; Estes, 2004; Ezra & Deckman, 1996; Hill et al., 2001; Salzstein et al., 2001; Scandura & Lankau, 1997), although some studies have found negative correlations, especially for women, or no relationship at all (Hochschild, 1989; Wharton, 1994). For example, if an employee asks for temporarily reduced hours in order to take care of a young child but then finds that their hours are permanently reduced to half- or part-time, this unanticipated loss in income could result in significant stress.

Few empirical studies have examined the associations that workplace and supervisory support have with work-life balance. Some previous studies have found workplace environments supportive of work-family balance to be positively related to employees' abilities to reconcile the competing demands of work and family (Behson, 2005; Frye & Breugh, 2004; Neal & Hammer, 2006; Secret & Sprang, 2001; Warren & Johnson, 1995). The present study found that those employees who perceived their organizational culture as supportive also tended to perceive having more flexible work schedules. These findings support the concept of boundary-spanning resources, which, in the case of working parents, often take the form of formal flexibility

policies that allow employees to take more control over their work schedules to accommodate their family responsibilities. Some theories suggest that informal policies such as workplace or supervisory support may affect employees' perceptions of their access to flexible work schedules, but empirical studies on these relationships are rare. One exception is a recent study on dual-earner couples caring for their children and aging parents, which found that workplaces with informal employee supports was positively associated with workplace flexibility (Neal & Hammer, 2006). The present study adds to our knowledge of the role of informal workplace supports in helping parents to balance work and family responsibilities.

The third and fourth research questions examined the mediating effects of flexible work schedules and work-life balance. It was hypothesized that flexible work schedules and work-life balance would account for a significant amount of the relationship between workplace policies and employee well-being for working parents.

This study found that employees who perceived their work schedule as flexible and reported having a more comfortable work-life balance reported more positive well-being. The perception of a flexible work schedule was positively associated with work-life balance, which in turn was associated with positive pathways to employee well-being. The effects of perceived supportive culture and supervisory support on employee well-being were mediated by flexible work schedules and work-life balance.

The current results clarified the role that perceived work-schedule flexibility plays in the associations among the perceptions of workplace support, supervisory support, work-schedule flexibility, and work-life balance. SEM analyses indicated that work-schedule flexibility indeed mediated these relationships. These results

revealed that both workplace support and supervisory support had direct effects on indices of work-life balance and indirect effects through work-schedule flexibility. The inconsistencies of previous findings on flexible work schedules can be partially explained by the inclusion of organizational support in the present study's quantitative model. For example, even if a company has a formal flexible work schedule policy in place, employees may be afraid to use it if the workplace is not supportive. All of this suggests that working parents often have difficulties balancing work-life responsibilities, and that they might benefit from an intervention such as supervisory support or counseling to help them deal with work-life conflict.

This study also clarified the role of work-life balance in the associations between flexible work schedules, work-life balance, and employee well-being. This result reveals that flexible work schedules have both a direct effect on indices of well-being and an indirect effect through work-life balance. This finding suggests that work-life balance programs could be an important component in stress management training to improve work-life balance and mental health issues.

Many working parents experience work-life conflict in their daily lives (FWI, 2004b; FWI, 2004c; Galinsky & Johnson, 1998). According to the results of the quantitative component of this study, employees who perceived having access to flexible work schedules also tended to report a higher level of work-life balance. Previous studies have measured work-life balance as an outcome of workplace policies. The present results suggest that work-life balance plays a mediating role in employee's well-being. Future researchers would do well to further examine whether work-life balance mediates the relationship between employee well-being and other measures of workplace flexibility. In short, the present study employed structural equation modeling to better isolate measurement error and confirms the positive

relationships between workplace flexibility, work-life balance, and employee well-being.

*Socio-economic Status, Work-life Balance, and Employee Well-being*

The next set of research questions (5 through 8) examined differences in employee well-being according to gender and income, the degree to which perceptions of flexible work schedules differed among single and coupled employees, the degree to which male and female employees experienced different levels of well-being, and differences in experiences of work-life balance among full-and part-time workers. It was hypothesized that higher levels of well-being would be reported by male working parents and those with higher incomes, that working parents who lived with a spouse or partner would have lower perceived job flexibility, and that part-time working parents would report higher levels of work-life balance than those who were working full time. Socioeconomic status (as measured by socioeconomic indicators such as gender, income, marital status, and job status) was used as a control variable in these analyses.

Many previous studies have revealed that there are gender differences in working parents' reported levels of work-life conflict (Emslie et al., 2004; Higgins et al., 1994) and feelings about work-family balance (Keene & Quadagno, 2004; Milkie and Peltola, 1999; Scandura & Lankau, 1997; Williams, 2000). Several studies have found that women experience more conflict between their roles as an employee and as a mother than men do with their respective roles (for a review, see Guest, 2002). Additionally, such role conflict has been found to be related to mental health problems (Emslie et al., 2004; Rosenfield, 1989) and stress about childcare (MacDonald et al., 2005) especially for women. Similarly, the present study found

that working women with children were more likely to report a lower level of well-being than men with children, suggesting that women might be more likely to suffer from stress or mental health issues as well. Future studies could be developed to examine how gender differences in the perceptions of work-life balance may affect the well-being of working parents.

Heymann et al. (1999) found that many working parents lack some kind of paid leave that would allow them to take care of their sick children, and that this may exacerbate both the challenges of providing care and the impacts on their children's health. In particular, low-income employees, particularly women with a lower socioeconomic status or single mothers, have been found to have more difficulties in balancing work and family responsibilities with an unpaid leave policy than their higher income counterparts (Barnett et al., 2003). In the present study, income was measured with a continuous variable that included four levels, ranging from less than \$20,000 to more than \$950,000. As hypothesized, high-income working parents were more likely to report a higher level of well-being than their low-income counterparts, suggesting that low-income employees were more vulnerable to a variety of issues related to work-life conflict, including stress.

Another finding from the present study was that working parents who were living with a spouse or partner were less likely to report having workplace flexibility than single working parents. This finding was unexpected, and the analyses do not seem to offer a solid explanation. However, it is possible that working parents who were living with a spouse or partner had a greater number of family responsibilities, including childcare, which may have made them feel that the "flexibility" offered to them by their jobs was insufficient or not flexible at all. Further research might explore whether working parents who live with a spouse or partner have more family-

related responsibilities, the desire to spend more time with their spouse and children, and/or less flexibility or time to do so.

Finally, as expected, the results revealed that part-time workers with children were more likely to report a higher level of work-life balance than full-time workers, perhaps because they had fewer work obligations that interfered with family life. This finding supports those of previous studies that found that working parents were likely to choose a part-time schedule as an effort to manage work demands and family responsibilities (Chung et al., 2007; Evans, 2002). However, as opposed to many full-time workers, part-time workers may face additional challenges and stress in caring for their family because of limited job security and benefits.

### *Summary*

As hypothesized, the results revealed that employees who perceived having a supportive organizational culture or supervisor also reported having access to more flexible work schedules and a more comfortable work-life balance; work-life balance, in turn, was associated with more positive well-being. It is possible that the presence of a more supportive work environment or supervisor eased employees' fears of negative sanctions when deciding whether to request a more flexible work schedule.

As anticipated in the hypotheses, perceptions of well-being differed across several socioeconomic characteristics. Specifically, working mothers were more likely to report a lower level of well-being than working fathers. Working parents with low incomes were more likely to report a lower level of well-being than their higher income counterparts. Working parents who lived with a spouse or partner were less likely to report having a flexible workplace than single working parents. Finally,

parents working part time were more likely to report a more comfortable work-life balance than parents working full time.

#### *Contributions to research*

These findings make a significant contribution to an understudied issue by using a more complex model than has been used in previous literature. In particular, the present results suggest that a flexible work schedule is important to employee well-being, and that this relationship is partially explained by the more comfortable work-life balance that parents with more flexible schedules enjoy. Also, the structural equation modeling utilized in this study is more capable of isolating measurement error than the regression methods used in previous studies. Further, as discussed below, the results of the present study also support border theory and the concept of boundary-spanning resources.

#### ***Extraordinary circumstances: the In-depth Interviews***

Research questions 9 through 12 were answered using in-depth interviews.

#### *Care of Chronically Ill and Disabled Children*

The ninth research question examined the ways in which parents of children with a chronic condition managed work and childcare demands.

Previous research has found that work-life balance is a challenging issue for working parents with a child under 18 years old (Halpern, 2005). Working parents generally struggle to deal with care responsibilities under a traditional work system that expects employees to be present in the workplace full time. Parents in our qualitative study had the additional responsibilities of providing persistent medical care and/or supervision for their chronically ill or disabled children, and thus they

faced more challenges in balancing work demands and care. Most parents also faced added financial burdens because of high medical costs. Many of these parents described that caring for a child with a chronic condition was like having another full-time job in addition to their paid job.

Our respondents vividly described the myriad challenges associated with the care of a child with a chronic illness or disability. For many chronically ill children, medications needed to be taken at all hours of the day, so parents had to organize their schedules to meet the child's medication demands. There were usually many other child-specific tasks that parents needed to juggle with their paid work, such as making frequent visits to the doctor, preparing healthy meals, shopping for items related to special needs, taking the child to and from school, and monitoring school related issues. Parents that had a younger child with a chronic illness or disability had even more responsibilities associated with care of more dependent infants and pre-schoolers.

The concept of "work-life balance" is somewhat different for these parents. Normally, work-life balance can be improved by decreasing the time spent at a paid job and by increasing the flexibility of scheduling; however, in extreme cases such as those faced by the respondents of this study, working parents may already have adjusted their work schedules or decreased their paid work time as much as possible. For these parents choices are limited, and achieving work-life balance may mean finding alternative ways to juggle their paid work and care responsibilities. In addition, such parents often have greater difficulties locating adequate childcare because of their child's complicated needs. For instance, Case V in this study explained that she did not even ask other family members to give medications to her child except in urgent cases because she was afraid that they might accidentally

confuse the complex medications and give the child the wrong one. Accordingly, the issue of work-life balance is not just related to an individual's beliefs about paid work, but also to social structural problems, which can significantly alter how parents make decisions about their work-life priorities.

In addition to work-life balance, emotional balance was another challenging issue for these parents. A majority of the parents in this study responded that it was very stressful to learn that their child had been diagnosed with a chronic condition. This finding supports family stress theory (Boss, 1988; Hill, 1958; McCubbin & McCubbin, 1993; McCubbin, McCubbin, Thompson, & Thompson, 1995; McCubbin & Patterson, 1983; Patterson, 1988; Patterson, 2002), which posits that new demands such as a child's chronic illness can generate long-term strains on parents. In the quantitative component of this study, perceptions of work-life balance were found to be positively associated with employee well-being. Considering the fact that working parents of a child with a chronic condition have more difficulties in dealing with work demands and care responsibilities, it seems very likely that such parents may experience greater stress or depression and thus potentially poorer well-being.

One such threat to well-being involved the unrelenting nature of the respondents' primary care responsibilities, especially for women. Most of the mothers in the study responded that they had responsibilities as a primary caregiver on a daily basis, while the few fathers in the study said that they had responsibilities as a secondary caregiver at home. Several other studies also confirm that women are still the primary caregivers in dual-earner families (Gaboda, 2007; Gerson, 2002; Hochschild, 1989; Keene and Quadagno, 2004), and this gender division of care may help to explain the lower levels of well-being found among women in our quantitative study.

### *Work-life Adjustment*

The tenth research question examined the ways in which parents coped with work-life balance in terms of life adjustment.

Most of the parents described that they continually adjusted their lives to address their children's needs. An adjustment to a work schedule can be temporary within a family without special needs; however, parents that have a child with a chronic medical condition continually adjust their lives in order to manage their child's long-term care. In this study, perceptions of work-life balance were related to the perceptions the flexibility of the job.

Our study also uncovered the following accounts of the actions that respondents had taken to adjust their work schedules in the years prior to the in-person interview: just over three quarters of parents had quit a job and a similar proportion had reduced their hours, and 17 of 27 parents had switched to a job that was less demanding or more flexible. These responses are similar to a list of adjustments found in a recent survey of caregivers in New Jersey (Gaboda, 2007). Half of our respondents stated that they had to have a part-time job with flexible hours to make it possible to be home to more closely monitor their child's condition, though those part-time positions often meant a lack of benefits. Many respondents said that they had looked for jobs that were not as demanding. Others had never even looked for jobs that did not offer a flexible schedule. This implies that these families are more likely to value flexible schedules over job security and the amount of pay, but they may put themselves at financial risk in prioritizing flexibility. In fact, the majority of our respondents reported that a flexible work schedule was one of the most important factors in being able to deal with care responsibilities and work demands.

Characteristics such as marital status and income affect the resources that parents have at their disposal to manage their responsibilities to work and family. Two-parent families often share the demands and negotiate life adjustment. For example, in Case A's situation, her husband stayed at home to take care of their child. When looking at coping strategies for work-life adjustment among married couples, some analysts have described the process of balancing work-life responsibilities between husband and wife as a strategy to construct "life as normal" (Robinson, 1993). Single working parents typically have more difficulties in arranging work and family responsibilities. Thus, it is not surprising that single parents like Cases B and C emphasized the importance of flexible work schedules. This suggests that flexible work schedules act as a critical coping and support mechanism for working parents, especially single parents, who have a chronically ill or disabled child.

In the FAAR Model, Patterson (1988) emphasized the importance of personal, family, and community resources to aid in achieving a more harmonious work-life balance. Not surprisingly, in the present study, the respondents who had many financial resources, including health insurance, were less likely to report stress regarding their family situation. Some parents who received high levels of social support from close relatives and friends were also less likely to report stress. Thus, as Patterson pointed out, family stress may vary with the availability of resources. Our findings tell us that, in addition to the FAAR model, work-schedule flexibility can be considered an important resource for achieving a balance between competing work and family demands. Additional research could examine the ways in which the availability of formal and informal resources and supports affect emotional well-being.

### *The Role of Work Policies*

The eleventh research question examined the role of formal and informal work policies in workers' perceptions of work-life balance, stress, and well-being.

As mentioned, most parents interviewed in this study answered that flexible work schedules were beneficial for them in managing work demands while caring for their chronically ill or disabled child. Parents who were able to make their own work hours were more likely to feel comfortable making changes in their work schedules to meet shifting family demands. However, respondents who worked a job that did not formally offer flexible schedules reported feeling stress when requesting a change in their schedule. The finding that flexibility reduces the stress of care giving was also found in a recent survey of New Jersey caregivers conducted by Rutgers University's Center for State Health Policy (Gaboda, 2007). Our findings also indicated that these parents need for a flexible schedule limited the pool of jobs available to them.

Even though parents with a chronically ill or disabled child continually adjust their work schedules, many are likely to need to take leave because of an unexpected situation. However, among the parents we interviewed, there were only five who had taken formal family leave. Half of our respondents were not eligible for FMLA sponsored leave. Some reported that they were eligible for FMLA and needed it, but they did not take the leave because of financial reasons. This finding is aligned with other research that indicates that a majority of parents either end their leave early or do not take leave because of financial concerns. Chung et al. (2007) surveyed 1,105 parents of children with special health needs and found that low income parents were less likely to have access to paid leave or to be able to afford unpaid leave, and that 64% of parents cut their leave short and returned to work even though their child was not better because the pay was not enough. Current unpaid leave policies seldom help

parents who have a child with a chronic condition (Chung et al., 2007), and instead of reducing parents' stress, the lack of leave often increases stress because the FMLA only allows 12 weeks of leave per year.

### *Strategies for Emotional Well-being*

The twelfth research question examined how parents coped with stress or depression.

Many parents reported reacting with shock, fear, stress, depression, and/or anxiety upon learning about their child's condition. Stressors included worries about financial concerns, social stigma regarding the disease, family responsibilities, and work demands. According to family stress theorists, if the family has adaptive resources such as financial savings and a broad extended family support circle, they may have the capability to adjust to the new situation and its demands (Hill, 1958; McCubbin & McCubbin, 1991; McCubbin, McCubbin, & Thompson, 1995; McCubbin & Patterson, 1983; Patterson, 1988; Patterson, 2002).

In this qualitative study, parents described several kinds of coping strategies to manage their depression or stress, including drawing on existing resources and identifying new ones. As some previous studies have found, support groups can be beneficial in that parents share common experiences and information about care (Bennett & DeLuca, 1996; Huws et al., 2001). However, there were only four people in our study who had attended a support group in which they communicated with others who shared a similar situation. Case E and Case J explained that attending a support group had helped lower their stress levels. However, some of the respondents expressed a lack of available time to attend such groups. Some respondents also expressed dissatisfaction with prior experiences in support groups, particularly

because parents tended to talk about their own complaints, which made them feel rather depressed. One way to remedy this would be to ensure that support groups are available, well-organized, and professionally facilitated. Studies of support groups, support networks, and online resources for parents who have a child with a disability or a chronic condition have shown the benefits that these resources have for reducing stress and improving parenting practices (Hamlett, Pellegrini, & Katz, 1992; Huws et al., 2001; Penn, 2005).

Some parents described using coping strategies such as reading a book, meditating, exercising, and drinking alcohol. Some other parents relied on solving their stress or depression by themselves. Though some of our sample drew on support groups, only a small percentage of the respondents used such networks. The present data do not allow for a full analysis of the diverse coping strategies used by parents, future research would do well to examine the extent to which parents utilize individual versus collective coping strategies to deal with work-life balance and stress. For example, drawing on family stress theory, research could investigate if and how stress management skills aid working parents in taking care of their chronically ill and disabled children and which work-life balance strategies are most effective in this regard.

***Common Findings from the NCSW and in-depth interviews: The Key Role of Work-Schedule Flexibility***

In summary, one common finding from both the NCSW data and the in-depth interviews is that flexible work schedules play a key role in enhancing the work-life balance of working parents. In the quantitative analyses, our study found that when working parents had a higher perception of work-schedule flexibility, they also had

more positive work-life balance and employee well-being. Most parents with a chronically ill or disabled child also reported that a flexible work schedule was very important to being able to manage the demands of work and childcare. In particular, parents emphasized the importance of formal flexible policies because they were more comfortable to use. While formal policies of flexibility are helpful to all working parents, they seem especially important for parents with chronically ill and disabled children because of the added financial and emotional strains associated with raising children with these special needs.

In addition, data from parents in both samples indicated that supportive workplace policies are important. However, parents of a chronically ill or disabled child tend to have extreme needs and require intensive emotional and financial resources and ongoing support to achieve work-life balance.

### *Theoretical Implications*

The quantitative component of this study was anchored in border theory (Clark, 2000) and the concept of boundary-spanning resources (Voydanoff, 2004). Boundary-spanning resources provide a foundation to understand workplace policies as they make it possible for working parents to shift between home and work responsibilities with a high level of work-life balance. Border theory provides a framework for identifying factors to facilitate work-life balance. The quantitative component of the present study is relevant to these theories because it examined the relationship between boundary-spanning resource variables: workplace support, supervisory support, work-schedule flexibility, work-life balance, and employee well-being. In particular, whereas the majority of previous research has focused on the effects of individual workplace policies (eg., work-schedule flexibility and on-site

childcare) on various employee outcomes such as work-family balance and stress, the present study examined the relationships among the five variables mentioned above.

The analyses of these relationships are able to offer two major new findings to the fields concerned with work-life balance. Particularly, parents who worked in a supportive environment tended to perceive a high level of workplace flexibility. Previous studies have often referred to work-schedule flexibility as a formal policy and workplace support and supervisory support as informal policies, and all three have generally been considered to impact employees in the same way without considering the relationships among them. However, this quantitative study found that these three constructs are interrelated, which means workplace support and supervisory support are directly associated with the perception of work-schedule flexibility. Another new finding, and one that enriches those of previous research, is that work-schedule flexibility and work-life balance appear to play significant mediating roles in the relationships between workplace support, supervisory support, and employee well-being, revealing that all of these constructs are more complicated than previously thought.

In support of the assertions of Voydanoff (2004), the findings from the present study indicate that boundary-spanning resources are positively associated with work-life balance. The complex links between the variables in the quantitative component of this study expand the framework of boundary-spanning resources and suggest that, in order to increase employees' perceptions of work-schedule flexibility, a supportive workplace culture and supervisor are important. In addition, the study offers an empirical analysis of a new theory, border theory, which has yet to be examined thoroughly in the literature. Based on this theory relationships were found among

organizational factors regarding time and work, and thus this study is able to make a meaningful contribution to the field.

The qualitative component of this study was based on family stress theory. We examined how parents with a chronically ill or disabled child managed their care responsibilities and paid employment. As Patterson (2002) outlined, upon receiving a diagnosis of their child's chronic disability, parents begin a long process of adapting their work and family lives to a unique set of stressors. Amidst the continuously changing family demands faced by the participants in the present study, parents who had access to a diverse and rich set of resources were more likely to have an easier time dealing with these stressors. These findings are in line with family stress theory.

The findings from this qualitative study showed that it is not easy for parents to achieve a balance in family functioning without a supportive system or policies at work. In general, the results support Patterson's FAAR model as mentioned above, and further suggest that the model should be expanded to include workplace support and work-schedule flexibility in order to more fully understand the process of successful adaptation. In other words, working parents' stress, adjustment, and adaptation need to be considered in both the work and family domains. However, work-related issues, such as managing work demands, are rarely considered in family stress theories. The present study illustrates that effectively dealing with family stress is not only achieved through resources at home, but also through the resources available to parents in the workplace. Indeed, in our study, most respondents played both primary caregiver and employee roles, representing a much different scenario than the traditional family structure roles assumed by family stress theorists. This qualitative study clarifies that the assumptions of family stress theory must be revised to recognize that many mothers of disabled and chronically ill children are in the

workforce. Additionally, the theory must be extended to consider what roles personal, family, work, and community resources play in parents' efforts to deal with family stress. Consequently, the present results expand upon the findings from previous studies and have important implications for family stress theory and practical applications for the social work field.

In summary, the results of the quantitative and qualitative components expand the theories used to frame the study. Additionally, some of the findings are new and contribute to filling research gaps of previous studies of work-life balance. In particular, the results of the quantitative study can be applied to improve the work-life balance and well-being of working parents, and the findings of the qualitative study may be useful for those who work with parents in the challenging circumstance of having a child with a chronic illness or disability. Given that this study includes both quantitative and qualitative components, it can be viewed as rich, theory-driven research to help us understand certain work-life issues of working parents.

### ***Recommendations for Further Research***

The quantitative component of this study used a secondary data set, and it was difficult to find an appropriate index of variables such as perceived flexibility and work-life balance. However, multiple indicators were used to measure work-life balance through SEM analyses, something that has yet to be done in the empirical research on this subject area. If the scale used in the present study can be developed for use in future studies, it may have a stronger validity. In addition, it is possible that unmeasured variables affected the relationships under analysis in the present study. Future research could expand and clarify the model used in this study by exploring

other mediators of the relationships between the perceptions of workplace policies and employee well-being.

Additionally, the quantitative data used in this study were cross-sectional in nature, which precludes an understanding of the changes in respondents' perceptions over time. Analyses of longitudinal data are needed to understand the short-term and long-term effects of workplace policies and to reduce the measurement error that can be caused by a cross-sectional data.

Specifically, the in-depth interviews were conducted at one point in time, and it is possible that the respondents would have expressed their feelings and situations differently at different periods. Longitudinal studies or multiple interviews with one respondent could provide a mechanism to verify the consistency or inconsistency of feelings or opinions. Also, focus-group interviews with parents who have children with similar conditions might generate additional insights into common and debatable issues as participants share experiences in group discussion. Therefore, using various qualitative methods could provide multi-dimensional information.

In addition, the qualitative study was limited to a small number of parents living in New Jersey. Future qualitative studies using larger and more diverse samples could provide a more intricate picture of employee situations to better assess their issues and needs.

The samples for both the quantitative and qualitative studies were limited to wage and salaried workers. Thus, neither study included alternative work settings such as working at home. More research needs to be conducted to investigate the appropriateness of policies across different types of occupations or industries.

### *Recommendations for Social Work Practice*

Social workers address issues of work-life balance with their clients in a variety of contexts and settings: as counselors, caseworkers, advocates, occupational social workers, educators, evaluators, liaisons, administrators, and policymakers. Knowledge of the research on factors affecting work-life balance could provide empirical support for these counseling, advocacy, and organizational efforts.

Counselors for working parents could incorporate the information from the results of the present quantitative study. The roles of occupational social workers vary according to their target populations, which may include employees, supervisors, and corporate managers (Bargal, 2000). In particular, regarding work-life balance issues, occupational social workers can assess organizational culture and supervisory support and how they are associated with perceptions of work-schedule flexibility. In addition, social workers might help to develop a more supportive workplace culture. They can also evaluate the perceptions that working parents have of work-life conflicts and intervene between supervisors or employers and employees. Providing counseling to workers could help workers to adjust their work demands and family responsibilities and facilitate better mental health. These contexts include counseling for working parents, working with families that have children with chronic disabilities, casework with clients involved with the many public assistance programs that have requirements for labor market participation and counseling through EAPs, which provide employees with professional, human support services.

While there is a large body of literature on social work practice in the field of disabilities, there is little information about the specific roles of social workers in dealing with the work-life balance issues of parents with children with chronic conditions. In general, with such families, social workers are likely to focus on

promoting family health and social support interventions, but those efforts may not encompass a family's work situation. The findings from this study indicate that social workers could draw on the evidence regarding the importance of flexible work schedules to assist clients with identifying and assembling employment situations that could facilitate better work-life balance. In addition, our respondents' comments regarding the difficulties involved in accessing and participating in social support groups might provide social workers with insights into how to better organize such efforts directed at parents with children with special needs.

This study's quantitative and qualitative analyses have some implications for casework with clients involved in the many public assistance programs, such as Temporary Assistance for Needy Families (TANF), that have requirements for labor market participation. As was discovered in the quantitative component of this study, low-income parents typically had more difficulties balancing work demands and care responsibilities. Low-income workers were less likely obtain program benefits, especially those involved in TANF, which for many families has been found to intensify poverty, income loss, and work-family conflicts (Albelda, 2001; Hasenfeld, 2000). When considering the findings of this study in the context of those from previous studies, it makes sense to create programs and benefits to assist in work-life balance.

Social workers are in an advantageous position to communicate with human resource professionals to organize intervention programs to meet the needs of workers. Social workers can advocate on the worker's behalf for more supportive work and family environments. Given the problems workers face, social workers can also function as an advocate for workers' interests by affecting workplace policies to support employees' positive work-life balance.

Mid-size and large companies that have EAPs typically offer some counseling programs and referral resources to help employees deal with work-life balance. However, counseling is not often recommended based on employees' daily work-life struggles unless there are visible issues such as substance abuse. Knowledge of the research on factors affecting work-life balance can potentially provide empirical support for efforts by occupational social workers and others as they advocate for shifts in the organizational culture and its supportive policies. Currently, EAPs tend to focus on unemployment or new employment issues (Iversen, 1998). Research by the University of Michigan School of Social Work has suggested that education and training should be offered to more people in the workplace through EAP programs (Root, 2000). However, there are no specific programs designed to address work-life conflicts in the workplace. Recently, the Rutgers University Center for State Health Policy (Gaboda, 2007) reported that mental health visits are twice as common for caregivers than for people without care responsibilities. EAP social workers could apply knowledge of factors associated with reduced stress and positive perceptions of work-life balance to their counseling and practice.

The findings of the quantitative study found that workplace and supervisory support were associated with working parents' perceptions of their access to a flexible work schedule and also to the state of their work-life balance. Thus, it is important to create interventions to help create a more supportive atmosphere in the workplace. Social workers are also in a unique position to educate workers and employers on work-life balance issues. An example of this would be educating workers on stress management of work-life conflicts. Social workers can also train managers and supervisors in supportive supervision at work. Programs that are implemented should be evaluated in order to examine the programs' effects and development. Social

workers are in an advantageous position to offer suggestions that benefit both employees and employers.

In addition, the qualitative study found that parents in the challenging circumstance of having a child with a chronic condition had greater difficulties to dealing with work demands and care responsibilities. Moreover, they were often emotionally and financially at risk because of a lack of health benefits. However, the work-life balance needs of parents of chronically ill or disabled children tend to be disregarded in the workplace because such parents represent a small minority of the labor force. To address this problem, social workers can liaison with labor unions and the Department of Labor to promote work-life balance. They can also collaborate with other professionals to give educational talks to employees when the social worker does not have the necessary expertise of strategies for achieving a more harmonious work-life balance. Thus, social workers can prevent potential conflicts and remedy existing problems in order to help enhance employees' well-being and work-life balance.

According to a survey of licensed social workers in the US by the Center for Health Workplace Studies & the NASW Center for Workforce Studies (2006), social workers who work with employees, supervisors, and corporate management only represent 0.7% of all social workers in the field. Moreover, few studies have addressed issues regarding work-family balance in social work practice (Bargal, 2000; Iversen, 1998; Masi & Jacobson, 2003). Social workers who work in human resource departments and labor union activists are in a position to shape practical programs to address the stress associated with work-family balance (Secret & Sprang, 2001). Furthermore, social workers need to follow up with intervention programs through

evaluations of exit programs such as EAPs or Work-Life Programs to determine if they have effectively addressed work-life conflicts.

In addition, regarding the implications for social work education, curricula for teaching about work and family issues need to be addressed with a comprehensive theoretical formation. There are very few social work programs that prepare students for careers in the workplace. Only 12 of the 91 accredited schools of social work in the US offer a specialization in occupational social work (Bargal, 2000). One school that does is the University of Southern California School of Social Work, which offers “Work & Life” as one of its areas of concentration. The school offers three specific courses in the concentration area: Clinical Intervention and Advanced Theories in Work Settings; Improving Work Life Through Social Policy and Managing Organizational Development and Change; and Program Development, Training, Grant Writing and Program Evaluation in Work Settings. A wider availability of such course offerings could advance future practitioners’ knowledge and applications of workplace issues in a variety of settings.

### ***Recommendations for Policymakers***

Recommendations for policymakers include policies by individual companies and public policies at the state and federal levels.

With respect to private policy, the findings suggest that there might be a number of relatively low-cost company-based policies, such as flexible work schedules, workplace support, and supervisory support, that could potentially enhance the perceived well-being of working parents, as previous research has suggested (FWI, 2004b). In particular, employees who work for small companies are not able to access the FMLA, so these employees may benefit from lower-cost, formal and

informal policies such as flexible schedules and supervisory support. Given the evidence from our quantitative study that a supportive workplace culture and supportive supervisor enhance employees' perceptions of the flexibility of the work schedules available to them, individual companies could design programs to promote a supportive work-life atmosphere including EAPs or work-life balance programs. Social workers engaged in EAPs could potentially assume key roles in program design and changing organizational culture (Cherin, 2000). Further research that produces evidence on the benefits to employers in terms of enhanced productivity and reduced turnover could support such policy and organizational change.

The interviews showed that it was not only important to make flexible policies available to employees, but also to make them formally accessible. Also, most parents in our study had changed their job to one offering greater flexibility, suggesting that if companies provide formally accessible flexible work schedules, they might benefit from reduced turnover. In addition to formal work-schedule flexibility, the qualitative findings suggest that policies beneficial to parents of chronically ill children would include paid leave policies such as paid sick days or vacation, equal or adequate pay and benefits for part-time workers, and more generous health insurance plans. If formal work-schedule flexibility is guaranteed and employees are able to take paid leave, then parents might be better able to balance their work demands with the needs of taking care of a child with a chronic illness or disability.

With respect to government programs, the present findings from the quantitative and qualitative studies suggest that efforts to expand paid leave coverage could increase program participation and employee well-being. While critics cite high costs and longer employee absences, some research indicates that paid leave would reduce staff turnover (Appelbaum & Milkman, 2006). Indeed, the data from this

qualitative study suggest that current leave policies should be reconsidered because families with chronically ill children were either not able or willing to take advantage of them. As noted previously, in a national survey of working individuals conducted in the year 2000, only 2% of employees had taken family leave to care for a seriously ill child in the 18 months preceding the data collection point (Appelbaum & Milkman, 2006; Waldfogel, 2001a). The FMLA and other workplace policies can be beneficial for parents, but benefits from other programs, such as welfare, SSI, or Medicaid, are often out of reach or too complicated to access because of strict eligibility requirements. Only 38% of children with special health care needs in NJ use Medicaid or the State Children's Health Insurance Program (Campaign for Children's Health Care, 2007). In order to overcome the limitations of the unpaid FMLA policy, California enacted a paid family leave law on July 1, 2004, which extended access to paid family leave to all workers in the state. This policy is funded by general state revenues and provides 6 weeks of coverage with 55% of the employee's wage up to a maximum of \$728.00 per week. In New Jersey, most employees have access to medical leave, which includes pregnancy- or birth-related medical situations through the state's TDI program. Unlike California, however, not all workers have access to paid leave to care for a child with a serious illness or chronic condition.

Our qualitative study recorded the stories of parents of children with a chronic condition, who were likely to work part time with fewer benefits and incur heavy costs associated with the child's illness, putting them at risk in terms of income and health security. These findings further illustrate the well-publicized gaps in health care policies. For instance, an estimated 16% of New Jersey adults who are providing care to older adults and people with disabilities are uninsured, and health policies that cover low income families with children with special needs typically do not

adequately cover medical needs (Gaboda, 2007; U.S. Department of Health and Human Services, 2004). The present research suggests, as well, the importance of policy initiatives that expand insurance coverage, particularly for those who currently rely on private, employer-based insurance. Models for such coverage have recently been adapted in a few states including Massachusetts, Maryland and Vermont, and similar initiatives are pending in other states (National Conference of State Legislatures, 2007). A universal health care system would guarantee access to health care as a right of citizenship, and this would be very beneficial to families with special needs (Campaign for Children's Health Care, 2007; Gaboda, 2007).

### *Limitations*

The NSCW data set used for the quantitative study is limited by its self-report survey design. As mentioned, the quantitative study used five construct variables to measure respondents' perceptions of work-schedule flexibility, perceived workplace support, perceived supervisory support, work-life balance, and employee well-being. There are several studies that discuss the rationale of using self-report measures such as perceived workplace or supervisory support (Jahn, Thompson, & Kopelman, 2003; Kottke & Sharafinski, 1988; Shore & Tetrick, 1991). Additionally, Wethington and Kessler (1986) found that the perception of the availability of support is more likely to be associated with predicting adjustment to stressful life events than received support. Although several measures of perceived variables have been validated in previous research, self-report items are subject to various sources of measurement error (Schwarz, 1999). In addition, because of the cross-sectional nature of this data, casual relationships cannot be inferred.

The qualitative study was based on subjective perceptions of working parents who had a child with a chronic illness or disability using non-probability sampling. Even though this qualitative study provides substantial information on the sample parents' work-life experiences and generates questions for further research, this study cannot be generalized because the sample size is small and not representative. Specifically, only a small number of parents from one state (New Jersey) were interviewed. Additionally, interviews were only offered in English, thus excluding non-English speaking individuals from contributing to the study. This study is also limited in other areas of diversity, specifically in terms of gender, race, education, and income. For instance, only two fathers were interviewed in this study. In addition, because the interviews were not conducted with spouses, there are limitations on how representative one spouse's data is of the family's work-family struggles. In addition, only four African American parents were interviewed in this study. Among our respondents, parental educational attainment was high: 40.7% of parents had a master's, doctoral, or professional degree. Therefore, this study is exploratory and should be replicated or expanded by including a larger, more diverse sample to better evaluate the relationships under analysis.

Another limitation is that the qualitative study did not identify parents' exact income level and only included a few extremely low-income parents. In addition, this study did not include unemployed parents. Considering that approximately 33% of parents either quit work or reduced their hours in order to care for their child with special health care needs (Campaign for Children's Health Care, 2007), unemployment is a real issue faced by this already challenged population and should be considered in future research. Finally, as mentioned in the Methods section, the

two data sets used in this study were distinct. Ideally, in-depth interviews should be conducted with respondents who were represented in the quantitative survey.

### *Conclusion*

The intention of this study was to contribute to our understanding of the association of perceived workplace support, supervisory support, work-schedule flexibility, work-life balance, and employee well-being. Towards this end, this study examined the relationships between supportive policies and perceived work-life balance among working parents. Quantitative and qualitative methods were used in this study to obtain a general picture of the work-life balance strategies used by working parents. In particular, it is hoped that the information gathered from the in-depth interviews will contribute to a richer understanding of the work-life experiences of parents caring for children with chronic conditions, as this population has rarely been studied in detail.

Previous studies based on conventional statistical techniques have contributed to the field's understanding of work-life balance by finding a direct linear relationship between workplace policies and employee outcomes. However, few studies have analyzed multiple workplace policies and important mediating factors such as work-life balance. In support of Voydanoff's (2004) concept of boundary-spanning resources and Clark's (2000) border theory, the SEM results revealed that working parents who perceived having a supportive organizational culture or supervisor reported having a more flexible work schedule. This finding represents a new and important contribution to the field. Additionally, it was found that positive perceptions of workplace support, supervisory support, and workplace flexibility were all associated with more positive work-life balance, which in turn was positively

associated with perceptions of well-being. This finding is important in that it demonstrates that flexible work schedules and work-life balance act as mediators between informal workplace policies and well-being.

The qualitative study, which used in-depth interviews, revealed several emerging issues that are important to working parents' coping strategies and well-being, including the importance of the availability of formal work-schedule flexibility policies and the supportiveness of the workplace. In particular, this study provides detailed information to supplement existing work-life balance studies that have generally not included parents of children with chronic conditions in their analyses. Also, this study will contribute to the expansion of family stress theory by adding work-life balance strategies to its model. As an additional suggestion based on family stress theory, expanded supportive resources, especially those that would support work-life balance, are needed at the work level. The results of this study highlight flexible policies, paid leave, and generous support as key issues in facilitating work-life balance.

These findings have several implications for social work. Specifically, the empirical evidence provided in this study could assist social workers in developing more effective intervention efforts by informing their counseling strategies and encouraging them to offer work-life balance programs to employees. Also, occupational social workers can use the findings from this study to develop new programs and evaluate existing ones such as EAPs. In terms of social work advocacy at the policy level, a key finding from both the quantitative and qualitative components of this study is the importance of flexible work schedules. The qualitative study suggests that paid leave and generous health care policies could benefit parents of children with chronic conditions. It is hoped that this research will not only provide

information to aid in creating more effective workplace interventions, but that it will also help establish work-life balance as an urgent issue in the social work field.

Finally the present findings also highlight the need to develop more supportive public and private policies for these families.

## APPENDICES

### *Appendix A: Measures Used in This Study*

Measures used in this study

All measures were derived from the Families and Work Institute's 2000 National Study of the Changing Workforce.

#### *A.1. Exogenous latent constructs*

##### *A.1.1. Perceived flexible work schedule*

3-Item, 5-point scale and 4-point scale respectively; complete to none response format and strongly disagree to strongly agree response format respectively

1 Flexhr: How much control would you say you have in scheduling your work hours – complete control, a lot, some, very little, or none?

2 Flexoff: How hard is it for you to take time off during your work day to take care of personal or family matters-very hard, somewhat hard, not too hard, or not at all hard?

3 Flexperf: Is this schedule perfect for you, okay but could be better, not very good, or not at all what you want?

##### *A.1.2. Perceived workplace support family policies*

4-Item, 4-point scale; strongly disagree to strongly agree response format

1 Unwrit: there is unwritten rule at my place of employment that you can't take care of family needs on company time.

2 Perahead: at my place of employment, employees who put their family or personal needs ahead of their jobs are not looked on favorably.

3 Attitude: if you have a problem managing your work and family responsibilities, the attitude at my place of employment is "You made your bed, now lie in it!"

4 Jobfirst: at my place of employment, employees have to choose between advancing in their jobs or devoting attention to their family or personal lives.

#### *A.1.3. Perceived supervisory support*

4-Item, 4-point scale; strongly disagree to strongly agree response format

1 Favori: my supervisor or manager is fair and doesn't show favoritism in responding to employees' personal or family needs.

2 Accommo: my supervisor or manager accommodates me when I have family or personal business to take care of – for example, medical appointments, meeting with child's teacher, etc.

3 Underst: my supervisor or manager is understanding when I talk about personal or family issues that affect my work.

4 Cares: my supervisor or manager really cares about the effects that work demands have on my personal family life.

#### *A.1.4. Perceived work-life balance*

3-Item, 4-point scale, 5-point scale, 4-point scale respectively; a lot to not at all, very easy to very difficult, very often to never response format respectively

1 Manage: how easy or difficult is it for you to manage the demands of your work and your personal or family life?

2 Nointer: how much do your job and your family life interfere with each other?

3 Time: how often have you not had enough time for your family or other important people in your life because of your job?

#### *A.2. Endogenous latent constructs*

5-Item, 5-point scale; very often to never response format

##### *A.2.1. Employee well-being*

1 Stress: how often have you felt nervous and stressed?

2 Minor: have you been bothered by minor health problems such as headaches, insomnia, or stomach upsets?

3 Sleep: how often have you had trouble sleeping to the point that it affected your performance on and off the job?

4 Control: how often have you felt that you were unable to control the important things in your life?

5 Feeling: how often have you felt that difficulties were piling up so high that you could not overcome them?

***Appendix B : Questionnaire 1***

This study is about how parents with a seriously ill child manage work-life balance. We are interviewing parents with a seriously ill child who currently has a job or who has worked for pay in the past 12 months. We hope you will take a few minutes to answer this questionnaire. If there are any questions you are unsure about, we will provide clarification. It should take you about 20 minutes to complete this questionnaire.

First, we would like to ask about your personal characteristics. Unless otherwise indicated, please check the **single** best response.

1. What is your highest level of education you have completed?

Less than high school

Some high school

High school graduate or GED

Some College, Associate's Degree or technical training

College graduate (Bachelor's Degree)

Graduate or Professional school

2. Which of the following best describes your current?

Married

Living with a partner

Separated

Divorced

Widowed

\_\_\_\_\_ Never married

3. Are you male or female?

\_\_\_\_\_ Male

\_\_\_\_\_ Female

4. How old are you? \_\_\_\_\_ years old

Now, we would like to ask your job and work experiences. Unless otherwise indicated, please check the **single** best response or write the best response.

5. Do you currently work for pay?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

6. How many employees in your workplace?

\_\_\_\_\_ 1-4 employees

\_\_\_\_\_ 5-49 employees

\_\_\_\_\_ 50-499 employees

\_\_\_\_\_ 500 or more employee

7. Are you working full-time or part-time at a job?

\_\_\_\_\_ Full-time

\_\_\_\_\_ Part-time

8. What is your specific job title? If you quit your job recently, please specify the recent job title. \_\_\_\_\_

9. In the past 12 months, how many weeks did you work at a paid job, whether part time or full-time, including time spent on paid vacation, paid sick time, or other paid leave?

\_\_\_\_\_ weeks

\_\_\_\_\_ did not work for pay in past 12 months

10. In the past 12 months, how many weeks were you unemployed-that is, weeks that you were not working at all, but were looking for a job?

\_\_\_\_\_ weeks

\_\_\_\_\_ was not unemployed in past 12 months

11. In the past 12 months, how many weeks were not working because you were on leave, such as sick leave, disability leave, maternity leave, or something else?

\_\_\_\_\_ weeks

If you took a leave, was this leave unpaid, or did you receive full or partial pay?

\_\_\_\_\_ Full paid leave

\_\_\_\_\_ Partial paid leave

\_\_\_\_\_ Unpaid leave

12. In the past 12 months, how many weeks were you not working at a paid job and not actively looking for work [for example, you were retired, at home caring for children, or student]?

\_\_\_\_\_ weeks

\_\_\_\_\_ does not apply to me

13. How many years have you worked in your *current* job? \_\_\_\_\_ years

14. How many hours per day do you typically work? \_\_\_\_\_ hours

15. How many hours per week do you typically work? \_\_\_\_\_ hour

16. Do you ever work from home in your *current* job?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

If yes, how many days per month do you typically work from home?

\_\_\_\_\_ days per month

17. On average, how many days per month are you away on business?

\_\_\_\_\_ days per month

18. On average, how many nights per month do you spend away from home on business?

\_\_\_\_\_ nights per month

19. Are your work hours flexible (i.e., are you free to set your own schedule, and come and go when you need to)?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

20. Does your supervisor allow you to occasionally arrive at work late or leave work early to deal with a family problem?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

Now, we would like to ask about your company's policies. Unless otherwise indicated, please check the single best response or write the best response.

21. My company has employee policies that are flexible enough to respond to employees' individual situations

Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	I have no idea

22. My company helps employees achieve a balance between their work and non-work responsibilities.

Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	I have no idea

23. My company expects employees to keep family matters out of the workplace.

Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	I have no idea

Now, we would like to ask about your children. Unless otherwise indicated, please check the single best response.

24. Please indicate whether the following problems have happened to anyone close to you in the past 12 months.

Child's Condition	Spouse or partner	Either of your parents, or the people who raised you	Any of your children	You
	Yes No D.A.*	Yes No D.A.*	Yes No D.A.*	Yes No D.A.*
a. Chronic illness or disability				
b. Asthma				
c. Cystic Fibrosis				
d. Frequent minor illnesses				
e. Emotional problems [e.g., sadness, anxiety]				
f. Alcohol or substance problems				
g. Financial problems				

[e.g., low income or heavy debts]				

Note. \*Dose not apply

25. Next, we are interested in how having a child with illness or disability, or condition such as asthma or cystic fibrosis may have changed your work situation. Which of the following changes did you and/or your spouse or partner make because you were living with children?

	You			Your spouse or partner		
	Yes	No	Does not apply	Yes	No	Dose not apply
a. Did either of you stop working at a job to stay home and care for the child who has asthma or cystic fibrosis?						
b. Did either of you stop working at a job to stay home and care for the child who has some other chronic condition?						
c. Did either of you cut back on the number of hours worked at a job to care for this child?						
d. Did either of you work longer hours to meet the added expenses of having a child with this condition?						
e. Did either of you switch to a different job that was less demanding or more flexible to be more available to this child?						

26. How many children do you have under 18? \_\_\_\_\_

27. Please indicate what sex and age they are.

\_\_\_\_\_

\_\_\_\_\_

Now, we are more interested in learning about the child who has asthma, cystic fibrosis, other chronic condition. Please check the **single** best response or write the best response.

28. Please tell us about this child.

Indicate what sex and age he/she is.

Age: \_\_\_\_\_ Sex: \_\_\_\_\_

(If you have more than one such child, please specify age and sex.)

\_\_\_\_\_

29. How long ago did you learn that your child has this condition?

\_\_\_\_\_ years

\_\_\_\_\_ months

30. How often does your child have a routine medical check up?

\_\_\_\_\_ once a month or more

\_\_\_\_\_ once every two months

\_\_\_\_\_ twice or more often a year

\_\_\_\_\_ once a year or less

31. Does your child need to manage his/her condition on a daily basis?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

32. Does your child need help or supervision managing his/her condition?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

If yes, do they need this help on a daily basis?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

Now, we are interested in how often your child misses school or child care. First we will ask about the past month. Then we will ask about the past year. Please check the **single** best response or write the best response.

33. In the **past month**, how often was your child not well enough to go to school or child care because of the asthma, cystic fibrosis or other chronic condition?

\_\_\_\_\_ once

\_\_\_\_\_ twice or more often

\_\_\_\_\_ 3 times

\_\_\_\_\_ more than 3 times

\_\_\_\_\_ did not miss school in past month

a) How many days was your child sick during the most recent episode?

\_\_\_\_\_ days

\_\_\_\_\_ does not apply

34. Thinking of the past **12 months**, how often was your child not well enough to go to school or child care because of the asthma, cystic fibrosis or other chronic condition?

\_\_\_\_\_ less than two times

\_\_\_\_\_ two or three times

\_\_\_\_\_ four or five times

\_\_\_\_\_ six to ten times

\_\_\_\_\_ more than 10 times

a) Thinking of the past **12 months**, how many days was your child unable to do regular activities during a typical episode?

\_\_\_\_\_ days

\_\_\_\_\_ does not apply

35. In the past **12 months**, did your child have an episode that required you to take the child to the hospital?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

\_\_\_\_\_ does not apply

If yes, how many times did you have to take your child to the hospital in the past year?

\_\_\_\_\_ number of times

36. Was your child treated in the emergency room and released?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

\_\_\_\_\_ does not apply

37. Was your child admitted to the hospital? If yes, how long did your child stay at the hospital?

\_\_\_\_\_ Yes \_\_\_\_\_ days

\_\_\_\_\_ No

\_\_\_\_\_ does not apply

Next, we would like to ask about care responsibilities. Please check the single best response or write the best response.

38. Do you have any relatives who live locally whom you care for? Please specify.

\_\_\_\_\_

39. Who does *most* of the housecleaning in your home?

\_\_\_\_\_ You

\_\_\_\_\_ Your partner

\_\_\_\_\_ Other relatives, friends, and neighbors

\_\_\_\_\_ Paid childcare or other paid worker

40. Who provides *most* of the care for your child/children during the day?

\_\_\_\_\_ You

\_\_\_\_\_ Your partner

\_\_\_\_\_ Other relatives, friends, and neighbors

\_\_\_\_\_ Paid childcare or other paid worker

\_\_\_\_\_ Children attend school and/or child care program

41. Who typically prepares dinner for your child/children each night?

\_\_\_\_\_ You

\_\_\_\_\_ Your partner

\_\_\_\_\_ Other relatives, friends, and neighbors

\_\_\_\_\_ Paid childcare or other paid worker

42. Who is primarily responsible for your child/children in the evenings?

\_\_\_\_\_ You

\_\_\_\_\_ Your partner

\_\_\_\_\_ Other relatives, friends, and neighbors

\_\_\_\_\_ Paid childcare or other paid worker

43. Who is primarily responsible for your child/children at night?

\_\_\_\_\_ You

- Your partner
- Other relatives, friends, and neighbors
- Paid childcare or other paid worker

Now, we would like to ask about care responsibilities for your child with asthma, cystic fibrosis or other chronic condition. Unless otherwise indicated, please check the single best response.

44. Who provides *most* of the care for this child during the day?

- You
- Your partner
- Other relatives, friends, and neighbors
- Paid childcare or other paid worker
- Children attend school and/or child care program

45. Who is primarily responsible for this child in the evenings?

- You
- Your partner
- Other relatives, friends, and neighbors
- Paid childcare or other paid worker

46. Who is primarily responsible for this child at night?

- You
- Your partner
- Other relatives, friends, and neighbors
- Paid childcare or other paid worker

47. Who most often takes this child for routine doctor's visits and check-ups?

- \_\_\_\_\_ You
- \_\_\_\_\_ Your partner
- \_\_\_\_\_ Other relatives, friends, and neighbors
- \_\_\_\_\_ Paid childcare or other paid worker
- \_\_\_\_\_ Child goes by themselves

48. Who most often helps this child manage condition on a daily basis?

- \_\_\_\_\_ You
- \_\_\_\_\_ Your partner
- \_\_\_\_\_ Other relatives, friends, and neighbors
- \_\_\_\_\_ Paid childcare or other paid worker
- \_\_\_\_\_ School staff (school nurse, guidance counselor, teacher, etc.)
- \_\_\_\_\_ Child manages by themselves

49. Who most often stays home with when the child is unable to go to school or child care?

- \_\_\_\_\_ You
- \_\_\_\_\_ Your partner
- \_\_\_\_\_ Other relatives, friends, and neighbors
- \_\_\_\_\_ Paid childcare or other paid worker
- \_\_\_\_\_ Child stays home alone

50. Who most often accompanies child to emergency room or hospital when there is a serious episode?

- \_\_\_\_\_ You
- \_\_\_\_\_ Your partner
- \_\_\_\_\_ You and your partner
- \_\_\_\_\_ Other relatives, friends, and neighbors

\_\_\_\_\_ Paid childcare or other paid worker

\_\_\_\_\_ Child stays home alone

\_\_\_\_\_ No episodes that serious

Finally, we would like to ask about some public policies that may apply to you.

Unless otherwise indicated, please check the single best response.

51. Have you ever seen, read or heard anything about a federal law called the “Family and Medical Leave Act” that provides eligible workers with job protection for up to 12 weeks when they take unpaid family or medical leave?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

52. Have you ever seen, read or heard anything about a state law called the “New Jersey Family Leave Act” that provides eligible workers with job protection for up to 12 weeks when they take unpaid family leave?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

53. Have you ever used the Family Medical Leave Act when you needed to take time off from work to

	Yes	No	Does not apply
Take child to doctor			
Stay home with child during an episode			
Take child to emergency room			
Stay with child in hospital			

54. How much FMLA leave did you use in past 12 months?

\_\_\_\_\_ days

\_\_\_\_\_ weeks

55. Have you ever used the NJFLA when you needed to take time off from work  
to

	Yes	No	Does not apply
Take child to doctor			
Stay home with child during an episode			
Take child to emergency room			
Stay with child in hospital			

56. How much New Jersey Family Leave Act leave did you use in past 12  
months?

\_\_\_\_\_ days

\_\_\_\_\_ weeks

Thank you for taking the time to fill out this questionnaire and share your experiences with us.

We plan to carry out in-depth interviews with some parents to hear more about your experiences with work-life balance. Please give us your telephone number if you would be willing to talk further with us.

Telephone #: \_\_\_\_\_

What is a convenient time for us to call you to make an appointment?

\_\_\_\_\_ am

\_\_\_\_\_ pm

### ***Appendix C : Interview Questionnaire***

Thank you for participating in our interview. This study is about how parents with a child with a chronic condition manage work-life balance. We are interviewing parents who currently have a job or who have worked for pay in the past 12 months. It will take one hour to complete this interview. Your answers are confidential and you will not be identified in any way.

#### **A. Introductory Questions**

##### **1) Work**

First, we are interested in hearing for you about your experiences in juggling work and family. Let's start with the job part.

- What is your job title (current or most recent job)? Can you tell me what you do in a job? What do you like? What do you dislike?
- Would you talk about your partner and her/his work? (interviewer probe for details about partner's situation)

##### **2) Family**

The next few questions are about your family. We would like to hear your story about your children.

- How many children do you have? In general, how are your children doing? (interviewer probe for details about ordinary children and a child who has asthma, cystic fibrosis or other chronic condition)
- Now, let's talk about how you are dealing with your child who has asthma, cystic fibrosis or other chronic condition. What is your child's illness? How long has your child had this condition? Has he/she ever been hospitalized for

this condition? How long was he/she in the hospital? (interviewer probe: could you tell me in detail?)

- How do you take care of your child who has this condition? How often do you do doctor's visits? How does the child manage daily tasks related to the condition? (interviewer probe: please say more about the child's progress.)
- What's your typical weekday like? Please describe.
- What's your typical weekend like? Please describe.

## **B. Core Questions:**

Many people find that their employer's policies help them with work and life balance. The next few questions are about policies in your company (at current or most recent job).

### **1) Policies**

- Are your work hours flexible (e.g., are you free to set your own schedule)?  
Would you please give me some examples of how you might use this flexibility to handle family issues? Can you tell me about the emotional effects of the kind of flexibility you have? How it affects the stress you are under?
- How much control would you say you have in scheduling your work hours?  
How do you manage your time?
- Can you take time off easily to care for your child with a chronic condition?  
What factors help you take time off to care for this child (interviewer probe: please say about your experiences).
- Do your coworkers help you to manage your work and personal or family life? (interviewer probe: please give me some examples of how your

coworkers help you formally and informally.)

- Does your company have a service that helps employees find child care if they need it? Please tell me about all of available services in your company? Could you tell me the strong points and weak points of these services with regard to your work-life balance?
- Have you ever seen, read or heard anything about the FMLA (Family and Medical Leave Act) and the NJFLA (New Jersey Family Leave Act)?  
(interviewer probe: where did you learn about it? How much FMLA/NJFLA leave did you use?) Did you take paid/unpaid family leave to take care of this child? How did you manage financially during the paid/unpaid family leave? How are you managing your financial situation at the current time?  
(interviewer probe: do you receive any assistance from other sources?)  
Looking back five years ago, how would you describe your financial situation at that time? Looking ahead five years into the future, what do you expect your financial situation will be like at that time?
- What do you think about the policies of your company such as flexibility and paid leave or help with child care and other services? (interviewer probe: please give me some examples.) If you are not satisfied with the policies in your company, what policies do you think would help you? Are you considering moving to a job with better policies?(interviewer probe: why or why not)
- Do you think you will still be working for (return to work for) this company one year from now? Five years from now?

## 2) Issues (concerns) by Time Sequence

Now, let me ask about your leave experiences for your child with a chronic condition. I am interested in what concerns did/do you have before the leave, during the leave, and after leave (if you finished a leave).

- Did you take a leave for this child? If yes, before you took a leave, what concerns did you have (e.g., paid leave, job loss...)? If you have a plan to take a leave, what concerns do you have now? Please tell me about your concerns.
- If you are on a leave now, what concerns do you have now (e.g., paid leave, job loss...)? (interviewer probe: please tell me in detail.)
- I would like to know whether you took (or plan to take) a long leave. How long were you (or do you expect to be) away from your job?
- After taking a leave, did you return (do you plan to return) to the same employer? Why? If you return (plan to return) to another employer, please tell me the reasons.
- What kinds of experiences did you have when you came back from a leave? After taking a leave, did you have any special problems and concerns? Or, if you are still on leave, what concerns do you have about returning to work?
- If you did not take a leave, have you changed your work schedule in any way? (probe: change from full-time to part-time? Work nights instead of day? Other)

### **3) Work-Life Satisfaction**

Now, we would like to know about how you handle work-family responsibilities.

We would also like to hear about how you have managed to care for this child.

We are also interested in your overall satisfaction with your life.

- Who helps to take care of this child? Do you have close relatives to help you care for this child? (interviewer probe: are you satisfied with how they help with this child?)
- Do other family members/friends/neighbors help you care for this child? Do you have other care givers or baby-sitters? Are you satisfied with how they help with this child?
- Do you have professional help caring for this child? Are you satisfied with how they help with this child?
- How difficult is it for you to care for this child? Would you say about it? (interview probe: very difficult, some difficult, difficult, difficult, not difficult at all) How many hours a week do you spend in extra care for this child?
- Do you feel that your emotional well being is good these days? How do your emotions affect your work and family life? For example, do worries about your child distract you when you are at work? Do work worries distract you when you are at home/hospital? Do you have a lot of interruptions at home or at workplace? What kinds of interruptions do you have?
- Please think of the work situation you are in now (or were in recently). Would you please give me some examples of the worst work situation and the best work situation? Looking back five years ago, what are differences in terms of your work situation.

#### **4) Mood, Emotional Well-Being, and Health**

Now, we are interested in your emotional and physical health. When you know your child has asthma, cystic fibrosis or other chronic condition, this might be

very stressful for you. The next few questions are about your feelings and your mood.

- When you learned that your child had asthma, cystic fibrosis or other chronic condition, how did this affect you? If it caused severe emotional stress or depression, how long did this serious stress or depression last? What would help alleviate your serious stress or depression?
- Do you think the demands of everyday life often get you down? When you get down, what do you usually do? How do you handle your emotions in your work place. (interviewer probe for details about parents' belief and survival or coping strategies)
- Do you feel stressed about work-family issues? What would help alleviate your stress? How do you solve your work and family problems emotionally?
- Do you feel time pressure? What would help alleviate your time pressure?
- How is your health these days? Do you have symptoms as a result of the burden of caring for this child? (interviewer probe: please tell me any kinds of symptoms you currently have.) Compared to five years ago, please say more about your emotional and physical changes. Would you talk about your partner and her/his health?
- What kind of effect does your job have on your physical health? Please describe.
- What kind of effect does your job have on your emotional or mental health? Please describe.

C. **Closing Questions:**

Finally, I would like to close our interview with a few general questions. Please tell me about yourself overall.

- How do you feel these days? If you have any positive factors to alleviate your work-life burden, please tell me about them. How do you keep things under control overall these days?
- Looking back five years ago, how would you describe your life overall at that time? (interviewer probe for details about overall life changes in terms of job carrier, family life, and etc)
- Looking ahead five years into the future, what do you expect your life overall will be like at that time?

### ***Appendix D: Introduction to Individual Interviews***

Family Leave and Work-Life Balance:

New Jersey Parents of Children with Chronic Conditions

Most parents today also hold jobs -- 70 percent of children have a mother who works for pay. While managing work and family responsibilities is a challenge for most employees, this is especially true for parents of a child with a chronic health condition such as asthma or cystic fibrosis. We are interviewing 20 to 30 parents with a child that has one of these conditions and who currently has a job or who has worked for pay in the past 12 months.

We will conduct an initial interview that takes 20 minutes. For a subset of parents who are able to spend more time, we will do a longer interview of one hour. Our goal is to learn more about the difficulties parents in this situation experience managing their work and family responsibilities and about the things that help them cope.

The information we obtain from these interviews will enable us to help companies and policy makers develop policies that can best support the efforts of parents of a child with a chronic medical condition.

The Rutgers University, 2005 President's Research in Service to New Jersey Award has funded the Center for Women and Work to examine these issues. The research team is led by Dr. Eileen Appelbaum of Rutgers University University School of Management and Labor Relations. Dr. Appelbaum has studied workplace practices and work-family issues for more than 20 years, and has published extensively on these topics. Soo Jung Jang is a Ph.D. candidate in Rutgers University School of Social Work.

This research is designed to illuminate the actual experiences and concerns of parents of children with chronic conditions in order to inform company policies and the public policymaking process. It will culminate in a report designed to help policymakers, employers, and parents.

No parent that participates in the study will be identified in the report. All interviews will be strictly confidential.

*Appendix E: Individual Informed Consent*

Dear Parent,

Thank you for agreeing to be interviewed as part of our project to study how parents with a child with a chronic medical condition balance the demands of their jobs and their families. We will be collecting data from parents with a seriously ill child who currently has or who has worked for pay in the past twelve months. Participation in this study is voluntary.

The interview will last approximately one hour. Your comments and responses to our questions will be kept strictly confidential. Data collected in this study will be securely stored in a locked cabinet and only researchers conducting this study will have access to it. No reference will be made in any reports that could link you to the study. You are, of course, free to terminate the interview at any time.

You will receive a \$10 gift certificate for your participation in this study. You will receive this gift certificate even if you decide to terminate the interview at any point before completion.

If you have any questions about the research project, please contact Dr. Eileen Appelbaum at Rutgers University. She can be reached at 732-932-4614 or by email at [eappelba@rci.rutgers.edu](mailto:eappelba@rci.rutgers.edu).

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact the Sponsored Programs Administrator in the Office of Research and Sponsored Programs at 732.932.0150 ext. 2104, or by email at [humansubjects@orsp.rutgers.edu](mailto:humansubjects@orsp.rutgers.edu). The sponsored Programs Administrator's mailing address is ORSP, 3 Rutgers Plaza, ASB Room 208, New Brunswick, NJ 08901.

Thank you for your willingness to participate in this important project.

Sincerely,

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Principal Investigator, Eileen Appelbaum, Ph.D.

I understand the procedures described above. My questions have been answered satisfactorily, and I agree to participate in this study. I have been given a copy of this document.

---

Respondent

Date

Rutgers University IRB #.....

Expiration Date: .....

\*Addendum to Proposal

Research Design and Collection of Qualitative Data

The research will focus on currently or recently employed parents with a child who has a serious chronic condition and who has had this condition for two or more years. We plan to contrast the experiences of parents whose children have episodes that often require hospitalization (e.g., cystic fibrosis) with those of children whose episodes may not (or may only occasionally) require hospitalization (e.g., asthma). We plan to recruit parents through hospital centers or other centers that provide specialized in-patient and out-patient care for these children.

Data collection will take place in two stages. First, we have developed a 20-minute questionnaire that allows parents to quickly check off the answers that apply to them. This questionnaire will enable the researchers to screen parents into the study. The researchers will analyze responses of parents who meet the following criteria:

- (1) Parent is currently employed or was employed at some time in the past 12 months
- (2) Child has a serious chronic illness
- (3) Child was diagnosed two or more years ago
- (4) Child has either been hospitalized in past 12 months or has had at least two episodes in past 12 months

Second, we will conduct a one-hour interview with a subset of the parents who complete the questionnaire and who indicate their willingness to be interviewed.

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