

**PARENTS RAISING CHILDREN WITH DISABILITIES: PREDICTORS  
AND DETERMINANTS OF WELLBEING**

A Dissertation

by

JAMES A. RESCH

Submitted to the Office of Graduate Studies of  
Texas A&M University  
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

August 2011

Major Subject: Counseling Psychology

Parents Raising Children with Disabilities:  
Predictors and Determinants of Wellbeing

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Approved by:

Co-Chairs of Committee,	Timothy R. Elliott Michael R. Benz
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## ABSTRACT

Parents Raising Children with Disabilities: Predictors  
and Determinants of Wellbeing. (August 2011)

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**Background:** The purpose of the present study was to identify and evaluate possible determinants of wellbeing and psychological adjustment in parents raising children with disabilities. Two studies drawing from the same sample of participants were conducted. **Method:** One-hundred and forty parents raising children with disabilities participated in this investigation. Participants completed a survey consisting of basic demographic characteristics of the parent, child-disability characteristics, parent problem solving ability, access to information and resources, environmental/social supports, appraisals of threat and growth, and measures of life satisfaction and physical/mental health. The purpose of study one was to evaluate possible determinants of parent wellbeing using a contextual model. The purpose of study two was to identify factors that predict depression risk status for parents raising children with disabilities. **Results:** Study one used structural equation modeling to test a hypothesized contextual model of parent wellbeing. Results of study one indicated strong model fit. In addition, after controlling for the contribution of parent demographic variables, the largest

contributors to parent wellbeing were parent problem solving ability, access to resources, environmental/social supports, and parent appraisals of threat. Child functional impairment was not significantly associated with parent wellbeing. Study two found that 19% of participants were at risk for depression. Moreover, using tests of mean differences and hierarchical logistic regression, study two found that parents at-risk for depression were significantly more likely to report physical health problems, ineffective problem solving abilities, lower family satisfaction, and more appraisals of threat compared to parents not at-risk for depression. These factors combined to predict significantly depression risk status with the at-risk group being identified with 83.3% accuracy. **Conclusion:** Implications related to the importance of resources and environmental/social supports, appraisals of threat and growth, and problem solving abilities on the overall wellbeing and emotional health of parents raising children with disabilities are discussed.

## **DEDICATION**

To Darlene, Alyssa, Jenna, and Giselle. I am eternally grateful for each of you. Your encouragement, smiles, and laughs have been the motivation I have needed to get me through this journey. I hope this research is meaningful and that it can make a difference, but I want you to know that this is not my magnum opus, you are! I love each of you to the stars and back.

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Special thanks are due to the Family to Family Network and to the amazing parents that participated in the study. I hope this work makes a difference for you and all parents that are faced with the unique challenge of raising children with special needs.

Finally, thanks to my amazing wife, our three little princesses, my brothers and sister, and my parents. Your faith, patience, and encouragement were exactly what I needed to push me along.

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## **INTRODUCTION: PARENTS RAISING CHILDREN WITH DISABILITIES**

Recently an increased emphasis on understanding the factors that influence the wellbeing of informal caregivers has emerged. Indeed, Talley and Crews (2007) asserted that the wellbeing of informal caregivers is a major public health concern. Consistent with this assertion, recent trends related to policy, interventions, and scientific inquiry have demonstrated the growing interest in informal caregivers. Over the last several years published studies related to informal caregivers have spanned the full gamut of scientific literature including special education, nursing, medicine, psychology, disability, social work, law, and public health. In addition, health and policy initiatives such as Healthy People 2010 (U.S. Department of Health and Human Services, 2000) and The Family Caregiver Support Act of 2001 (Raina et al., 2005) promote objectives related to the health and wellbeing of informal caregivers and their families. Private organizations have also taken notice of the importance of caregiver issues (e.g., the American Psychological Association has created a task force with an explicit focus on the wellbeing of informal caregivers; Chamberlin, 2009). The focus of the present study concerns a specific subset of informal caregivers: parents raising children with disabilities.

Because of the preeminent importance of the parent's role in raising children, it is essential that parents have the skills, personal health, and environmental/social

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This dissertation follows the style of *Rehabilitation Psychology*.

supports necessary to optimally fulfill their responsibilities. For parents raising children with disabilities these factors are particularly important because their unique parenting responsibilities can potentially make them more vulnerable to experience psychosocial distress (Parish, Rose, Grinstein-Wiess, Richman & Andrews, 2008), health problems, and a more negative perception of their quality of life (Feldman et al., 2007; Ones, Yilmaz, Cetinkaya & Calgar, 2002). Aggravating these risks is the finding that parents of children with disabilities engage in preventative health practices less frequently than other parents (Navaie-Waliser et al., 2002). These findings are troubling as parents of children with disabilities have the most significant impact on the overall wellbeing of their child (compared to educators and healthcare providers, for example; Elliott & Mullins, 2004) and positive outcomes related to the child with the disability and the entire family are likely strongly related to the parent's level of personal wellbeing. Furthermore, the unique responsibilities and roles of parents raising children with disabilities likely could not be optimally fulfilled by any other organization, and it is equally doubtful that society in general could subsume these roles. For example, the economic impact of informal caregivers, estimated to be approximately \$200 billion annually (Arno, Levine, & Memmott, 1999), represents an irreplaceable contribution to society. Given the singular influence of parents and their unparalleled contribution to their families and to society, the increased interest in the caregiver experience is not surprising. A particularly important area of inquiry relates to their overall wellbeing. Thus, an appropriate question is: What factors influence the wellbeing of parents raising children with disabilities?

## **Parent Wellbeing**

### ***Individual Characteristics***

Two types of individual characteristics have often been considered when attempting to understand the experiences of parents raising children with disabilities, child-specific and parent specific. Of these, the individual characteristics of the child with the disability may be the most studied. Plant and Sanders (2007) found that parents identified child-specific parameters as the reason for four out their five most stressful parenting responsibilities. Specifically, their study discovered that difficult tasks related to caring for a child with a disability (i.e., feeding, toileting, etc.), child behavior difficulties and child disability severity significantly predicted the amount of stress parents endorsed. Other studies have also investigated the effects disability type, disability severity, and behavior problems have on parent wellbeing. Disability type has not always been found to be a very good predictor of parent adjustment and wellbeing (Friedrich, 1979). This should not be too surprising given the variability of disability characteristics within and between specific types of disability categories. Other child-specific problems, such as bowel and bladder continence, have also been shown to be significantly predictive of parent wellbeing (Macias, Roberts, Saylor, & Fussell, 2006).

In terms of the parent-specific variables that influence parent wellbeing, basic demographic information and personality characteristics are some of the more important factors that have been studied in the past. For example, gender has been shown to be correlated with parent wellbeing (e.g., mothers in general tend to report more depressive symptoms and family problems than do fathers; Bristol, Gallagher & Schopler, 1988).

Age of the parent also influences wellbeing among families of children with developmental disabilities. For example, increased parental age is associated with lower satisfaction with family functioning (Failla & Jones, 1991) and higher levels of parenting stress (Macias, Clifford, Saylor & Kreh, 2001). Characteristics such as race have also been shown to be associated with the wellbeing of parents of children with disabilities (Darling & Gallagher, 2004). Other studies have demonstrated that factors such as optimism, a sense of control, and being able to find meaning from diverse situations and circumstances have buffering effects against challenging life events (Taylor, Kemeny, Reed, Bower & Gruenwald, 2000).

Another parent-specific variable that may influence parent wellbeing is problem solving ability. Due to the unique responsibilities parents of children with disabilities often have, the ability to efficiently and successfully solve problems is an important skill. Proponents of social problem solving theory argue that individuals with effective problem solving skills will be more likely to deal effectively with future problems (e.g., challenges associated with the responsibilities of raising a child with a disability); as well as be able to cope with the negative emotions that accompany life's challenges (Chang, D'Zurilla, & Sanna, 2004). Conversely, individuals with irrational beliefs regarding their problems tend to be at higher risk for emotional distress such as depression (Nezu, Wilkins, & Nezu, 2004), and research has demonstrated that problem solving training for informal caregivers is effective in decreasing depression, health complaints, and poor problem solving styles (Elliott, Berry & Grant, 2009; Rivera, Elliott, Berry & Grant, 2008).

### ***Resources and Environmental/Social Characteristics***

Another determinant of parent wellbeing is related to resources and environmental/social characteristics. Resources and environmental/social characteristics refer to the variables that are not person, child or disability specific, but rather a product of surrounding social and environmental systems with which parents interact. Green (2007) found that most parents of children with disabilities associated the “burden of care” with socio-cultural constraints and not with child-specific problems. Lollar (2008) has recommended that more attention be paid to the barriers parents encounter posed by limited resources and environmental/social restrictions. Recent studies (e.g., Green, 2003, 2007; Resch et al., 2010; Worcester, Nesman, Mendez & Keller, 2008) have attempted to study these barriers and they have essentially concluded that creating supportive social environments for parents and their families is vital for positive adjustment. Some of the environmental variables that contribute to parent wellbeing are associated with financial barriers, community and social inclusion, family stress, and obtaining access to necessary information and services (Resch et al., 2010; Worcester et al., 2008).

Interacting with service delivery systems is an important and time consuming aspect of a parent’s role. Parents often report serious challenges navigating these systems, which is troubling because parent (as well as child and family) wellbeing is largely dependent on their ability to obtain and sustain essential supports (Freedman & Boyer, 2000; McCarthy & Stough, 1999). Attempting to obtain and maintain these services is often frustrating and extremely difficult due to inflexible policies, unclear

and/or restrictive eligibility criteria, and significant wait times (Freedman & Boyer, 2000; McCarthy & Stough, 1999). Problems accessing needed services leaves parents feeling defeated and stressed (Krauss et al., 2001) which subsequently may have a negative impact on their overall wellbeing.

Difficulties related to family income and financial problems are well documented in studies of parent wellbeing. In a study of children with attention deficit hyperactivity disorder, Baldwin, Brown, and Milan (1995) found that problems related to finances accounted for 42% of the variance in overall stress reported by parents, compared to just 18% of the variance explained by symptomatic behavior related to the child's disorder. Notably, annual healthcare costs for children with disabilities are often three times higher than the annual healthcare costs for other children (Newacheck & Kim, 2005). This finding is not unexpected given that children with disabilities are significantly more likely to visit the doctor and to be admitted to the hospital compared to children without disabilities (Boyle, Decoufle, & Yeargin-Allsopp, 1994). Moreover, children with disabilities often live in families experiencing substantial financial hardships (i.e., poverty; Fujiura & Yamaki, 2000), but even families whose income is above the poverty level can experience significant material hardship (Parish et al., 2008). The financial burden experienced by parents raising children with disabilities is often caused by increased costs related to the child's needs and employment challenges (e.g. loss of employment or inability to work resulting from parenting tasks; Murphy, Christian, Caplin & Young, 2006; Parish et al., 2008; Worcester et al., 2008). In turn, not being able to work may cause parents to feel isolated and dissatisfied with their lives (Shearn



& Todd, 2000). Feeling isolated is also due to negative stereotypes associated with a disability (e.g., low expectations and stigma; Green, 2003) which may impede the development of a sufficient social network. Mothers of children with disabilities are particularly more likely to have smaller social networks and fewer friends than mothers without a child with a disability (Kazak & Wilcox, 1984). In general, however, it is not only the mother that feels isolated as studies show that the entire family can feel cut off from their communities (Freedman & Boyer, 2000; Worcester et al., 2008).

### ***Appraisal of Growth and Threat***

A parent's appraisal of their situations and circumstances may have a significant direct influence on parent coping and wellbeing in addition to serving as a mediator between person-specific, social/environmental variables, and overall parent wellbeing (Elliott & Warren, 2007). Previous studies provide evidence for the importance of the appraisal process. Kronenberger and Thompson (1992) discovered that parent's cognitive appraisals of stress were more predictive of depression and anxiety than the child's disability severity. Another study discovered that cognitive appraisals of parenting tasks had a mediating effect between disability severity and parental stress, and also proved to be a significant independent predictor of perceived parental stress (Plant & Sanders, 2007). Notably, parent's appraisals can be both positive and negative. Hastings and Taunt (2002) asserted that positive and negative appraisals can take place at the same time and may be predicted by distinct variables. Recent studies have verified that parents often perceive positive growth (Konrad, 2006) and increased resiliency (Bayat, 2007) through their experiences parenting a child with a disability. Moreover,

parents of children with disabilities have often reported feeling more grateful for life, an improved understanding and acceptance of individual and group diversity, more mental/emotional endurance, a more cohesive family, and increased spirituality (Donelan et al., 2002; Green, 2007; Murphy et al., 2006; Taunt & Hastings, 2002). Simultaneously, however, parents may also perceive that challenges and barriers related to raising a child with a disability have the potential to harm or threaten certain aspects of their lives (e.g., future goals, financial security, relationships with others), and Hassall and Rose (2005) have recommended that this side of the appraisal process should also be considered in the examination of parent wellbeing. Emerging evidence has demonstrated the potentially important role of threat appraisals. For example, Pakenham (2001) found that parents of children with cerebral palsy who reported better adjustment had lower appraisals of threat compared to parents with more adjustment difficulties.

The purpose of the present study was to examine the influence of the variables heretofore mentioned on the wellbeing of parents raising children with disabilities. Drawing from the same participant sample, two studies were conducted. The first study sought to determine the relative contribution of each measured variable on parent wellbeing using a theoretically-based contextual model. The second study's goal was to identify characteristics of parents that may place them at increased risk for major depression. The following section presents the details on the participants, procedures, and measures for both studies. Subsequently, an overview of each study will be provided along with each study's analysis, results, and discussion. Finally, limitations and future directions will be presented.

## **Method**

### ***Participants***

Participants for this study were recruited with the assistance of a large statewide parent organization. To qualify for this study, potential participants had to be the parent/legal guardian and primary caregiver of a child with a disability. All the parents affiliated with the parent organization met these criteria. Each geographic area of the state was targeted for recruitment in an attempt to adequately sample all major racial/ethnic groups and population demographics (i.e., non-rural and rural locations). Over 80 counties in Texas were represented by the parents that belonged to the parent organization used to help recruit participants for this study. While this only accounts for about one third of the 254 total counties in Texas, it is important to note that approximately half the counties in Texas are federally designated frontier counties which indicate they are sparsely populated. To recruit participants an initial email was sent to the parents affiliated with the statewide parent organization. This initial email had two purposes: (a) to gather basic demographic data about the overall sample using a short (five question) online survey and (b) to recruit parents for participation in the larger survey. A total of 270 parents completed the short demographic survey. Of those, 242 (90%) agreed to complete the larger survey. Of these 242 parents, 140 (58%) participated in the online survey and were included in the analysis. Previous studies using an online survey have yielded a fairly large range of response rates (e.g., 25% to 75%; Sue & Ritter, 2007) and a response rate of at least 50% is considered adequate for

a web-based survey (Kittleson, 1997). Table 1 presents the demographic data of the 140 participants.

### ***Procedure***

Qualtrics (2010), an online survey tool used to facilitate data collection and analysis, was used for this study. Using a web-based survey to collect data from parents of children with disabilities is particularly appropriate as research has shown that at least 75% of parents of children with disabilities use the internet and over 90% of those that do use it at home. Moreover, 72% of parents raising children with disabilities use the internet to obtain direct information related to their unique parenting roles (Blackburn & Read, 2005). Prior to beginning formal data collection, the survey was piloted with eight parents of children with disabilities to test the survey instruments, survey format, and average time to complete the survey. It was determined that most parents would take approximately 30 minutes to complete the survey in one sitting. Since a large percentage of the state residents speak Spanish as their primary language, the survey was also available in Spanish. Some of the measures used in this study already had Spanish language versions. For those measures that did not, Spanish translations were conducted by a team of three bilingual staff. A primary translator was assigned to translate each measure and two secondary translators reviewed the translation for accuracy.

The 242 parents that indicated their willingness to participate in the study were sent an email with a brief explanation of the study along with a unique electronic link to the web-based survey. The purpose of the unique electronic link was to allow parents to

Table 1

*Demographic Characteristics of Parents and Children*

Parent Characteristics	Mean	SD	Child Characteristics	n(140)	%
Parent Age	46	8.64	Gender		
Number of children in family	2.3	1.02	Female	39	27.3
	n(140)	%	Male	99	69.2
Ethnicity			Primary Disability*		
Asian	3	2.1	Auditory Impairment	2	1.4
Black/African-American	7	4.9	Autism	50	35.0
Hispanic/Latino/a	17	11.9	Deaf-Blind	1	.7
White/European-American	113	79.0	Emotional Disturbance	4	2.8
Education Level			Learning Disabled	7	4.9
Less than high school	2	1.4	Mental Retardation	25	17.5
High school graduate	7	4.9	Multiple Disabilities	26	18.2
Some college	40	28.0	Orthopedic Impairment	6	4.2
College graduate or higher	91	63.6	Other Health Impaired	13	9.1
Employment Status			Speech Impairment	2	1.4
Not working	45	31.5	Traumatic Brain Injury	2	1.4
Sporadic/Seasonal	6	4.2	Visual Impairment	1	.7
Part-time	34	23.8	Child Age*		
Full-time	55	38.5	0-3	3	2.1
Primary Language			3-5	10	7.0
Other	1	0.7	5-11	47	32.9
Spanish	7	4.9	11-16	40	28.0
English	132	92.3	17-21	25	17.5
Household Income			Post Graduate	13	9.1
Under \$25,000	10	7			
\$25,000-\$49,000	21	14.7			
\$50,000-\$79,000	41	28.7			
\$80,000-\$150,000	39	27.3			
Over \$150,000	26	18.2			

Note. \*Categories are consistent with those used in Texas

save their survey if they were unable to complete it during one sitting. In addition, the unique link was connected to each participant's IP address and could only be accessed by them. This allowed researchers to be sure that only parents belonging to the statewide parent organization were participating in the study. Upon accessing the unique link participants read a more detailed explanation about the study, their rights as participants, a statement about any potential risks and rewards of participating, a statement about confidentiality, and the contact information for the principal investigator, the professor chairing this research project, and the Institutional Review Board at Texas A&M University. Participants were explained that by completing the survey they gave their consent to participate.

### ***Measures***

The survey consisted of measures that gathered data targeting the following areas: (a) individual characteristics of the parent and child with the disability (b) resources and environmental/social supports, (c) appraisals of threat and growth, and (d) parent wellbeing.

***Individual Characteristics.*** Two types of child-specific information were gathered. First, participants were asked to share basic demographic information about their child with a disability (i.e., age, gender, disability type). Second, information related to disability severity was solicited. To this end a portion of the Personal Care Assessment Form (PCAF; available at <http://pcaf.tamu.edu/>) was used. For this study, participants were asked to answer 12 questions from the PCAF that related to the child's capacity to complete activities of daily living (ADL). The PCAF was created for the

Texas Health and Human Services Commission and items were informed by the Minimum Data Set for Nursing Home Resident Assessment (MDS; Hawes, Phillips, Morris, Mor, & Fries, 1997) and the MDS for Home Care (MDS-HC; Morris, Fries, Carpenter, & Bernabei, 1997). The ADL questions on the PCAF inquire about the child with the disability's need for assistance over the past seven days in several different areas (e.g., bed mobility, eating, transfers, toilet use, personal hygiene, bathing, and continence) using a six item Likert scale ranging from total independence to total dependence. Two of the continence questions (bowel and bladder continence) from the PCAF-ADL use a similar 6 item Likert scale ranging from continent to always/almost always incontinent. A third question regarding continence asks if the child with the disability is continent during the night and the response choices are yes/no. The first part of the ADL items are scored from 0-5 (less to more dependence) and then all the items are added together to get a total score. Higher scores on the PCAF-ADL indicate less ability to perform ADLs independently and, therefore, more functional impairment. The two questions regarding urinary and bowel continence were also added together with higher scores indicating more incontinence. The question about nighttime continence was coded as 1 (not continent during the night) and 0 (continent during the night). Initial investigations of the PCAF-ADL have shown high internal consistency ( $\alpha = .94$ ; Fournier, Davis, Patnaik, Elliott, Dyer, et al., 2010). This study yielded similar reliability results ( $\alpha$  for PCAF-ADL = .95 and  $\alpha$  for urinary and bowel continence = .94).

Participants completed a demographic questionnaire designed to gather basic information such as their age, race, annual household income, occupation, number of

children, and education level. To assess for their overall problem solving abilities, participants completed the Social Problem Solving Inventory-Revised 10 item version (SPSI-R-10). The SPSI-R-10 is a self-report questionnaire which uses a 5-point Likert scale ranging from 0, not at all true of me, to 4, extremely true of me. The 10 item version was created in an effort to quickly and effectively measure overall social problem solving abilities while simultaneously preserving the strong psychometric properties of previous versions of the instrument (Dreer, Berry, Rivera, Snow, Elliott, et al., 2009). These goals appeared to have been achieved as initial testing using Rasch scaling suggests that the 10-item version is psychometrically equivalent to the 25-item version. The 10-item version gives a unidimensional, global score of one's social problem solving ability. Concurrent validity was assessed by comparing the 10-item global score to other commonly used instruments that measure depression and satisfaction with life (Dreer et al., 2009). Overall, the 10-item version of the SPSI-R demonstrated "stable psychometric properties and may be substituted for its longer counterparts without loss of predictive power" (Dreer et al., 2009, p. 664). Scores on the SPSI-R-10 range from 0-40 with higher scores indicating better problem solving abilities. Internal consistency of the SPSI-R-10 for this study was adequate ( $\alpha = .74$ ).

***Resources and Environmental/Social Characteristics.*** Given the aim of this study, a survey instrument which specifically addressed some of the concerns related to resources and environmental/social supports was needed. To this end, the Resources and Environmental/Social Supports-Questionnaire (RESS-Q) was created. The items on the RESS-Q were rationally developed with input from both researchers and parents of



children with disabilities. The RESS-Q is also based on theoretical and empirical evidence which suggests parents of children with disabilities encounter several barriers related to resources and supports in the surrounding community and their social environments (e.g., Beckman, 2002; Chwalisz, 1992; Gaugler, Kane, & Langlois, 2000; Minnes, 1988; Resch et al., 2010; Worcester et al., 2008). The purpose of the RESS-Q is to provide a way to examine limitations caused by environmental restrictions as recommended by Lollar (2008) to allow researchers to assess for specific person-environment match problems.

The RESS-Q consists of 13 statements aimed at determining if parents encounter problems related to access to information and services, financial barriers, and social/community inclusion. Example questions are: “Important information related to the needs of my child is usually readily available and easy to understand”, “Our insurance plan usually covers the majority of the health care expenses for my child with a disability”, and “I am pleased with my social life and the number of opportunities I have to spend with friends and neighbors”. The RESS-Q uses a five-point Likert scale ranging from 1 (mostly disagree) to 5 (mostly agree). From these 13 items a total score is derived ranging from 13 to 65 with higher scores indicating more environmental and social supports. Reliability analysis of the RESS-Q for this study revealed strong internal consistency ( $\alpha = .79$ ).

Four additional open-ended questions were asked in order to have participants share, in their own words, any other challenges they commonly encountered related to environmental/social supports. Gathering qualitative data from parents is an optimal way

to give them more of a voice in studies such as this (Resch et al., 2010; Worcester et al., 2008). For this study, qualitative data was used to help describe and define the quantitative results.

***Appraisals of Threat and Growth.*** The Post Traumatic Growth Inventory (PTGI) was used to assess for ways in which participants believed they had benefited or grown from raising a child with a disability. The PTGI is a 21 item questionnaire developed by Tedeschi and Calhoun (1996) for assessing positive outcomes for persons who have experienced a traumatic event. Items require participants to rate the extent to which they believe certain areas of their life have positively changed in five areas (a) personal strength, (b) spiritual change, (c) relating to others, (d) new possibilities, and (e) appreciation of life. Each question used the same Likert scale format ranging from 0 (*I did not experience this change*) to 5 (*I experienced this change to a very great degree*). For this study a total score for the PTGI, ranging from 0-105, was used with higher scores reflecting more perceived benefit. Previous research has found the PTGI to be a reliable (e.g., full scale  $\alpha = .90$ ) and valid instrument in measuring growth when facing challenges (Tedeschi & Calhoun, 1996). Internal consistency of the PTGI for this study was also high (full scale  $\alpha = .94$ ).

It is important to note that having a child with a disability may not be considered a traumatic event by many participants. It was determined, however, that the PTGI would be an adequate way to measure the parent's overall perception of benefits gained by raising a child with a disability because it asks questions related to important ways in which people can grow when faced with challenges. Prior research supports the use of

the PTGI in non-trauma studies such as this (Anderson & Lopez-Baez, 2008). For this particular study the individual items on the PTGI were not altered; however, the instructions to complete the PTGI included a slight alteration in order to reflect the purpose of this study. Specifically, rather than being asked to respond to the questions based on a particular crisis or traumatic event, parents were asked to answer the questions based on their experiences related to raising a child with a disability. One additional open-ended question was included at the end of the PTGI and parents were invited to share in their own words how having a child with a disability has positively impacted their life.

To measure appraisals of threat a brief measure previously used in caregiver research was used (e.g., Pakenham, 2001; Stanton & Snider, 1993). This measure is based on a model originally created by Folkman et al. (1986) that measures threat, challenge and controllability. For this study only the threat subscale was used. The threat scale consists of seven questions asking participants to appraise the degree to which they think raising a child with a disability could threaten certain areas of their life. Specifically, the threat scale uses a seven-point scale and asks participants to rate how much (from low potential to high potential) they believe their main parenting problem associated with raising a child with a disability had the potential for harm in certain areas (e.g., important life goals, relationships with others, and their physical wellbeing). In previous studies this questionnaire has demonstrated strong psychometric properties (e.g., Stanton & Snider, 1993; Pakenham, 2001). Internal consistency of the threat scale for this study was high ( $\alpha = .89$ ).

***Parent Wellbeing.*** Four instruments were used to measure parent wellbeing. As an overall measure of the parent's physical and mental/emotional wellbeing, version one (standard 4-week recall) of the Short Form-12 (SF-12; Ware, Kosinski, & Keller, 1996) was used. The SF-12 is a 12 item self report health survey that assesses one's overall physical and mental health. The SF-12 was created as a short version of the SF-36 and items represent each of the eight domains on the original SF-36: physical functioning, social functioning, role functioning, mental health, pain, emotional well-being, energy, and general health. The SF-12 yields two main factors: the Mental Component Summary (MCS) and the Physical Component Summary (PCS; Ware et al., 1996). The SF-12 has been found to be a reliable and valid measurement tool. Test-retest reliability for the SF-12 has been shown to be between .86 and .89 for the PCS score and between .76 and .77 for the MCS score (Ware et al., 1996). No less than 20 previously published studies providing evidence for the empirical validity of the SF-36 have been replicated on the SF-12. Moreover, the SF-12 has high criterion and construct validity. The mental and physical health components of the SF-12 had correlations of .95 and .96 with the SF-36, and the SF-36 has proven to be highly correlated with several other common health surveys (Ware, 1993; Ware et al., 1996). The MCS and PCS scores were used in the present study with higher scores on each scale indicating better physical and emotional/mental health.

To measure the parent's subjective rating of life satisfaction, the Satisfaction with Life Scale (SWLS) was used. The SWLS is a five item instrument developed by Diener, Emmons, Larson and Griffin (1985) used to measure one's overall subjective

wellbeing. The SWLS requires respondents to rate how much they agree with five different statements regarding their overall life satisfaction using a 7-point Likert scale ranging from mostly agree to mostly disagree. Each item is scored from one to seven for a total score ranging from five (low life satisfaction) to 35 (high life satisfaction). Higher scores on the SWLS suggest greater general life satisfaction. Initial testing of the SWLS demonstrated strong psychometric properties. A two-month test-retest analysis yielded a correlation of .82 and the internal consistency was also high ( $\alpha = .87$ ). Subsequent testing of the SWLS established it as a highly valid measure as well (Deiner et al, 1985). Internal consistency of the SWLS for this study was high ( $\alpha = .86$ ).

Family adaptability and cohesion was measured using a modified version of the Family Satisfaction Scale (FSS; Underhill, Lobello & Fine, 2004). The FSS consists of 14 items and was created by Olson and a team of researchers (Olson & Wilson, 1982) to measure family cohesion and adaptability. The FSS has often been used in research involving the study of injuries and disabilities (Perlesz, Kinsella & Crowe, 2000; Warren, Wrigley, Yoels & Fine, 1996; Webb, Wrigley, Yoels & Fine, 1995). The FSS uses a Likert-scale scoring format (1 = dissatisfied, 2 = somewhat dissatisfied, 3 = generally satisfied, 4 = very satisfied, 5 = extremely satisfied) with possible scores ranging from 14 to 70. Higher scores indicate greater family satisfaction. Initial reliability and validity studies performed by Olson and Wilson (1982) yielded an alpha coefficient of .92. Internal consistency of the FSS for this study was similarly high ( $\alpha = .90$ ).

To measure for possible depression the Patient Health Questionnaire-9 (PHQ9) was used. The PHQ9 is a nine item self-report questionnaire taken from the full PHQ and is an appendix used to assess one's level of depression. A particular strength of the PHQ9 is that the nine questions reflect the nine criteria of which the DSM-IV depressive disorders are based (Kroenke, Spitzer, & Williams, 2001). The PHQ9 asks respondents to choose one of four Likert-scale responses (0 = not at all, 1 = several days, 2 = more than half the days, 3 = nearly everyday) to questions asking about their mental/emotional health over the previous two week period. The range of scores for the PHQ9 are 0-27 with a score between 0-4 indicating no depression, 5-9 indicating mild depression, 10-14 indicating moderate depression, 15-19 indicating moderately severe depression, and  $\geq 20$  indicating severe depression.

Reliability and validity studies of the PHQ9 have yielded results indicating sound psychometric properties. Internal consistency of the PHQ9 has been shown to be high. A study involving two different patient populations produced Cronbach's alphas of .86 and .89. Additionally, test-retest reliability also had a high correlation at .84 and a ROC analysis produced an area under the curve for the PHQ9 of .95 when diagnosing depression (Kroenke et al., 2001). Additionally, the PHQ 9 was highly correlated with the Mental Health Inventory-5 (MHI-5) a five-item mental health questionnaire, which indicates high construct validity (Kroenke et al., 2001). Criteria validity was established by conducting 580 structured interviews by mental health professionals that were blinded to the patient's PHQ9 scores. Results from these interviews showed that individuals who scored high ( $\geq 10$ ) on the PHQ9 were between 7 to 13.6 times more

likely to be diagnosed with depression by the mental health professional. On the other hand, individuals scoring low ( $\leq 4$ ) on the PHQ9 had a less than 1/25 chance of having depression (Kroenke et al., 2001). Internal consistency of the PHQ9 for this study was  $\alpha = .85$ .

## STUDY ONE

Research during the past several decades has produced an impressive amount of important information regarding the experiences of parents raising children with disabilities. The problem, however, with much of the previous research on parent wellbeing is that it is often disjointed, non-systematic, and primarily descriptive, lacking a clear linkage to services, interventions, and policy. Perhaps these shortcomings are because much of this research is not theory-driven and researchers tend to focus on the examination of a small number of single variables (Pakenham, 2001) which then account for a small portion of the variance in parent wellbeing. To overcome some of these shortcomings studies that consider a more complete and contextual view of the parent experience are needed. Researchers have often conceptualized the experiences of parents using several different, but somewhat similar, theories. For example, previous studies (e.g., Beckman 2002; Kazak & Wilcox, 1984; Worcester et al., 2008) have suggested Bronfenbrenner's ecological framework theory as a way to conceptualize the experiences of parents and families of children with disabilities. Stress process theory (e.g., Gaugler et al., 2000; Katerndahl & Parchman, 2002) and family stress theory (Minnes, 1988) have also been used to illustrate the diverse factors that influence the wellbeing of individuals caring for someone with a disability. Although each of these theories has unique characteristics, they have one important, metatheoretical position in common: The wellbeing of parents of children with disabilities is influenced by many factors (i.e., individual characteristics, resources, and environmental/social supports).



Therefore, when studying their experiences, an approach which accounts for this complexity is essential. A shortcoming of these theoretical frameworks, however, is their failure to account for the important influence of the appraisal process. Appraisals of growth and threat likely directly influence parent wellbeing, but equally notable is their potential role as a mediating variable between individual characteristics, resources and environmental/social supports, and parent wellbeing.

The purpose of study one is to understand the determinants of parent wellbeing by simultaneously investigating the roles of individual characteristics and environmental/social characteristics. In addition, the contribution of the parent's appraisals of growth and threat will be investigated to understand their contribution to parent wellbeing. To examine these factors simultaneously a model similar to the dynamic process model proposed by Elliott and Warren (2007) will be used. This model is consistent with the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) in that it recognizes the limitations and barriers to wellbeing that can exist at both the individual and environmental/social levels. In addition, this model adds to the WHO classification and addresses shortcoming of other conceptualizations (i.e., ecological models and stress models) by also emphasizing the importance of each individual's appraisal process (Elliott & Warren, 2007; see Figure 1). Although the dynamic process model was originally conceptualized to examine coping and adaptation of the individual with the disability, Resch et al.

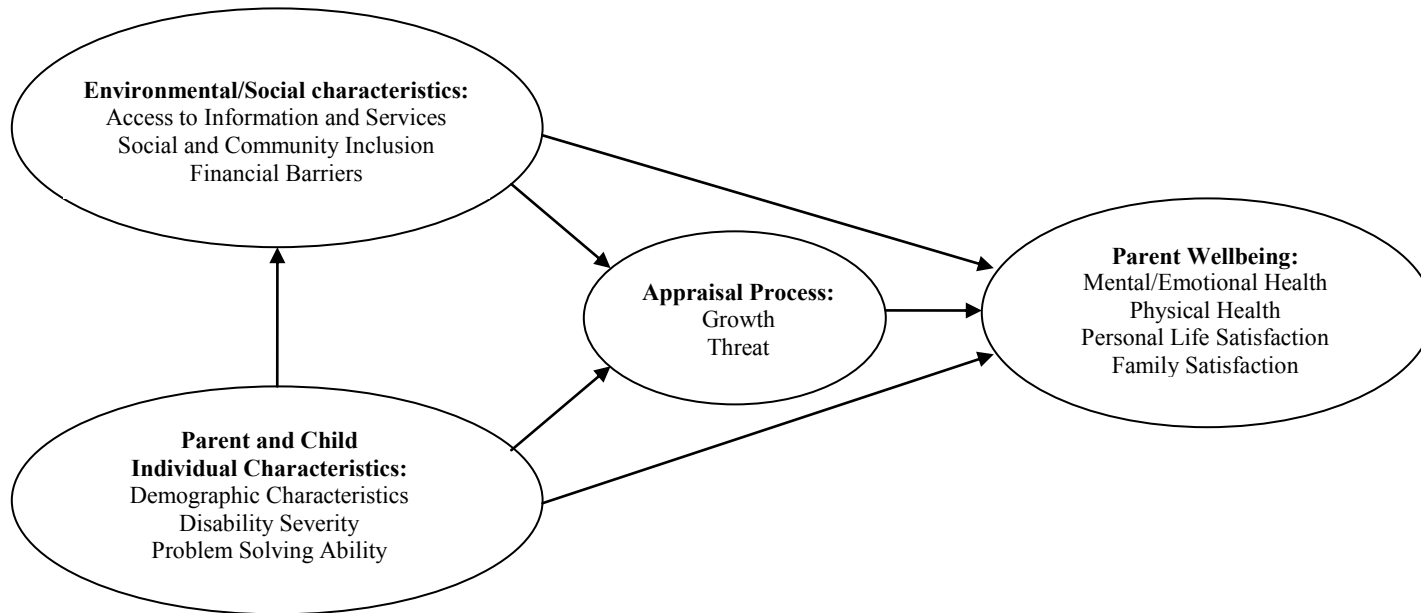


Figure 1. Conceptual Model of the Factors that Influence Parent Wellbeing.

Table 2

*Means, SDs, and Correlations of Variables*

Measure	Mean	SD	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Parent age	45.96	8.64	-																
2. Education	3.57#	.66	.12	-															
3. Income	3.36#	1.17	.11	.45**	-														
4. Employment Status	2.02#	.87	.23*	-.01	-.16	-													
5. Number of Children	2.31	1.02	.12	.08	.20*	-.12	-												
6. Child Age	3.81#	1.17	.64**	.02	.03	.15	.09	-											
7. PCAF-ADL	11.71	11.99	-.24**	.10	-.08	-.11	.01	-.17*	-										
8. U/B Continence.	2.49	3.77	-.34**	.01	-.13	-.11	.07	-.34**	.67**	-									
9. Night Continence	.30	.45	-.20*	.10	.01	-.06	-.04	-.22*	.44**	.61**	-								
10. SPSI	29.63	5.25	.25**	.19	.19	.05	.07	.14	.01	-.10	-.12	-							
11. RESSQ	35.43	9.20	-.04	-.01	-.01	.18	-.10	-.04	-.15	-.05	.02	-.01	-						
12. Threat	20.75	10.35	.03	.11	.10	-.11	.01	.13	.11	.13	.13	-.21*	-.55**	-					
13. PTGI	60.02	22.80	-.16	-.09	.05	.02	.03	.09	.15	.14	.10	.13	-.02	.02	-				
14. FSS	48.25	11.06	-.09	-.06	.13	-.06	-.14	.08	.05	-.10	-.03	.23**	.38**	-.40**	.21*	-			
15. SWLS	22.23	6.75	-.04	-.03	.16	-.08	.04	.18*	.02	-.01	-.06	.31**	.31**	-.29*	.23*	.48**	-		
16. PCS	51.43	10.24	-.10	.04	.19*	-.05	-.02	-.06	-.02	-.12	-.12	-.08	.11	-.10	.01	.15	.01	-	
17. MCS	43.52	10.78	.11	-.05	-.02	.13	-.10	.17*	.03	-.02	-.03	.35**	.29**	-.39**	.08	.43**	.35**	-.16	-

Note. \* =  $p < .05$ .; \*\* =  $p < .01$ .; # These questions were categorical, but were treated as continuous variables (see study one data analysis section for a detailed explanation)

(2010) have suggested that this model may also be useful in examining the wellbeing of parents raising a child with a disability.

Conceptualizing parental wellbeing using this dynamic process model has several important implications. First, the relative contribution of each variable in the path of parent wellbeing can be evaluated. Second, this model represents a contextual explanation of issues that influence parent wellbeing allowing for a more accurate conceptualization of the parent's experience. Third, this model builds on previous research about parent wellbeing by examining both environmental and personal characteristics together. Fourth, the potential direct and mediating role of appraisals can be assessed in this model. Given these implications, study one will address the following research questions: (a) Which variables in the model make the greatest relative contribution to parent wellbeing and (b) What are the direct and indirect (mediating) contributions of appraisals of growth and threat to parent wellbeing?

### **Data Analysis**

Table 2 presents the sample statistics (means, standard deviations, and intercorrelations) of the observed variables. Structural Equation Modeling (SEM) was used to test the hypothesized model. Prior to testing the model, three preliminary data analysis steps were performed. First, the observed data were assessed for univariate normality which can be an indicator of multivariate normality (Weston, Gore, Chan, & Catlano, 2008). An examination of the skewness and kurtosis of each variable revealed that observed data were distributed normally for each variable. Second, correlations between each variable were analyzed to test for problems related to multicollinearity and

to ensure that correlations were in their expected directions. No problems related to multicollinearity were found and each significant correlation between variables was in the expected direction. A few of the variables in the model were categorical (i.e., demographic variables: child age, parent education, household income, and employment status), but were treated as continuous variables in the analysis as each one was in an ascending order (e.g., 1, less than high school education to 4, college graduate and higher, or 1, not working/sporadic to 3, full-time). Byrne (2001) suggested that SEM analysis can treat categorical variables as continuous variables with little negative effect. Third, data were checked for missing values. As is the case with many studies such as this, some participants did not answer all the questions on the survey. Most of the participants, however, answered all or most of the questions and no large scale systematic patterns of missing data were identified in the analysis. Following these initial steps the hypothesized model was tested. Data were analyzed using MPlus (Muthen & Muthen, 2010) statistics software which is especially appropriate for doing SEM. The estimation method used was full information maximum likelihood. When doing SEM large samples sizes (>200) are generally recommended as they increase the likelihood of having good model fit in addition to the researcher's ability to estimate more complex models by including more indicators (Weston et al., 2008). However, Kline (2005) suggests that a sample size between 100 and 200 is adequate for SEM and results of this analysis yielded strong model fit using each of the most common fit indices.

Table 3

*Standardized Path Estimates and Factor Loadings of Measured Variables*

Variable	Est.	S.E.	P-Value
<b>Parent Wellbeing</b>			
<i>Disability Severity</i>	.13	.101	.214
<i>Resources and Environmental/Social Supports</i>	.34**	.108	.002
<i>Problem Solving</i>	.29***	.090	.001
<i>Threat</i>	-.37**	.118	.001
<i>Growth</i>	.19*	.091	.037
<b>Threat</b>			
<i>Disability Severity</i>	.18*	.082	.003
<i>Resources and Environmental/Social Supports</i>	-.54***	.069	.000
<i>Problem Solving</i>	-.26***	.079	.001
<b>Growth</b>			
<i>Disability Severity</i>	.24*	.097	.015
<i>Resources and Environmental/Social Supports</i>	-0.016	.095	.862
<i>Problem Solving</i>	.13	.093	.157
<b>Factor Loadings on Parent Wellbeing</b>			
<i>FSS</i>	.72***	.064	.000
<i>SWLS</i>	.65***	.069	.000
<i>MCS</i>	.57***	.077	.000
<i>PCS</i>	.07	.105	.484
<b>Factor Loadings on Disability Severity</b>			
<i>Urinary and Bowel Continence</i>	.97***	.048	.000
<i>Nighttime Continence</i>	.63***	.061	.000
<i>PCAF-ADL</i>	.69***	.058	.000

Note. \* =  $p < .05$ ; \*\* =  $p < .01$ ; \*\*\* =  $p < .001$

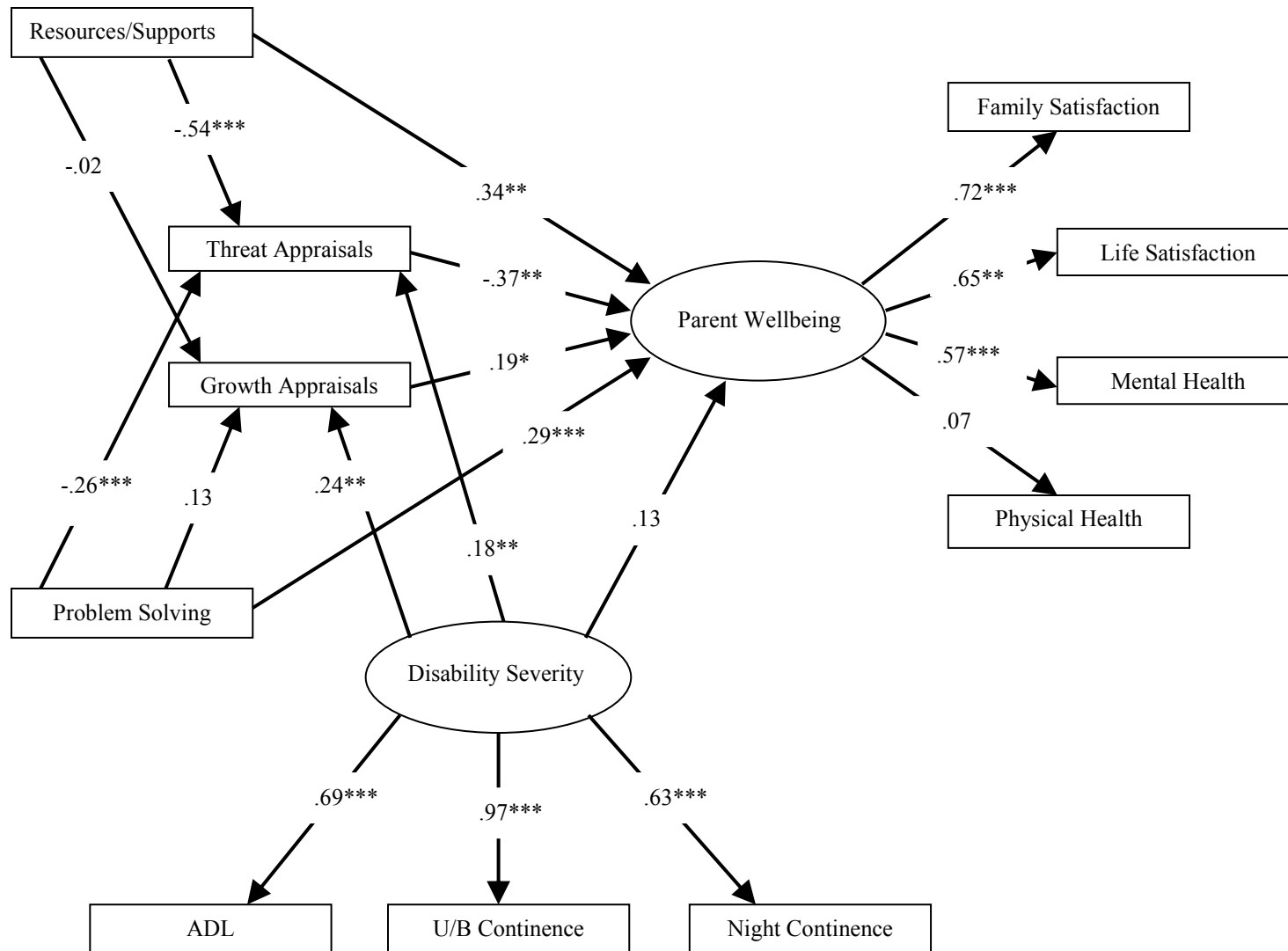


Figure 2. Analyzed Model with Standardized Path Estimates.

Note:  $*$  =  $p < .05$ ;  $**$  =  $p < .01$ ;  $***$  =  $p < .001$ ; Chi-Square (72) = 90.33,  $p = .074$ ; CFI = .95; TLI = .91; RMSEA = .04; SRMR = .05

## Results

Significant path estimates of the hypothesized structural model along with the significant factor loadings of the observed variables on the two latent variables are presented in Figure 2 and all path estimates and factor loadings are included in Table 3. The contributions of parent/child demographic variables on threat, growth, resources and environmental/social supports, and problem solving ability were also estimated in order to control for their contribution and these are presented in Table 4. Qualitative data will be included throughout the results section to further describe, define, and enhance the quantitative results.

### *Model Fit*

Standardized path coefficients were estimated and, in addition to chi-square statistics, model fit was tested using several of the most common fit indices including, Comparative Fit Index (CFI), Tucker Lewis Index (TLI), Standardized Root Mean Square Residual (SRMR), and Root Mean Square Error of Approximation (RMSEA). Good model fit with these indices is achieved with a CFI and TLI of at least .90 and optimally  $>.95$ , a RMSEA of  $<.06$ , a SRMR of  $<.08$  and a non-significant chi-square statistic (Weston et al., 2008). Analysis revealed that the hypothesized structural model was indeed a good fitting model:  $\chi^2 (72) = 89.20, p = .074$ ; CFI = .95; TLI = .91; RMSEA = .04; and SRMR = .05. In addition, the hypothesized model accounted for 67% of the total variance in the main endogenous latent variable, parent wellbeing. A significant amount of variance was also accounted for in most of the observed



Table 4

*Standardized Path Estimates of Demographic Variables*

	Est.	S.E.	P-Value		Est.	S.E.	P-Value
<b>Parent Wellbeing</b>				<b>Problem Solving</b>			
<i>Employment Status</i>	-.15	.08	.007	<i>Employment Status</i>	.035	.087	.684
<i>Household Income</i>	.220	.097	.023	<i>Household Income</i>	.118	.095	.214
<i>Number of Children</i>	-.216**	.083	.009	<i>Number of Children</i>	.010	.086	.904
<i>Education Level</i>	-.144	.096	.133	<i>Education Level</i>	.101	.096	.292
<i>Child Age</i>	.318***	.096	.001	<i>Parent Age</i>	.213*	.088	.015
<b>Threat</b>				<b>Resources and Support</b>			
<i>Employment Status</i>	.010	.079	.287	<i>Employment Status</i>	.188*	.089	.034
<i>Household Income</i>	.105	.087	.229	<i>Household Income</i>	.041	.101	.689
<i>Number of Children</i>	-.081	.076	.287	<i>Number of Children</i>	-.054	.089	.544
<i>Education Level</i>	.082	.097	.395	<i>Education Level</i>	-.045	.099	.654
<i>Child Age</i>	.205*	.086	.017	<i>Child Age</i>	-.071	.088	.415
<b>Growth</b>							
<i>Employment Status</i>	.049	.091	.589				
<i>Household Income</i>	.156	.101	.121				
<i>Number of Children</i>	-.025	.091	.784				
<i>Education Level</i>	-.179	.104	.085				
<i>Child Age</i>	.147	.093	.115				

Note. \* =  $p < .05$ ; \*\* =  $p < .01$ ; \*\*\* =  $p < .001$

endogenous variables. Fifty-one percent of the variance was accounted for in family satisfaction, 42% in life satisfaction, 33% in mental health, and 41% in appraisal of threat. Only a small and statistically non-significant amount of variance was accounted for in the remaining endogenous variables (i.e., resources = 4%; problem solving 10%; growth = 9%; physical health 1%).

### ***Predictors of Parent Wellbeing***

***Individual Characteristics.*** The path from disability severity to parent wellbeing was not significant ( $\beta = .13$ ,  $p = .21$ ), suggesting the child's functional impairment did not significantly contribute to parent wellbeing. Parental problem solving ability did significantly contribute to parent wellbeing ( $\beta = .29$ ,  $p = .001$ ). Parents reporting more effective problem solving abilities were associated with higher levels of overall wellbeing. Several demographic variables were also tested for their contribution to parent wellbeing. Child age ( $\beta = .29$ ,  $p = .002$ ), the number of children parents have ( $\beta = -.20$ ,  $p = .02$ ), the parent's employment status ( $\beta = -.18$ ,  $p = .03$ ), and household income ( $\beta = .21$ ,  $p = .03$ ) significantly contributed to parent wellbeing. Conversely, parent's education level ( $\beta = -.14$ ,  $p = .15$ ) did not significantly predict parent wellbeing. Parents with older children with a disability and higher household income tended to report higher levels of overall wellbeing. Conversely, parents who worked more hours per week and had more children at home experienced lower levels of wellbeing.

***Environmental/Social Characteristics.*** The results of this analysis reveal that resources and environmental/social supports ( $\beta = .34$ ,  $p = .002$ ) made one of the most significant contributions to the principal outcome variable, parent wellbeing. This finding

suggests that as parents have increased access to information and resources, feel included and accepted in their surrounding social environment, and encounter fewer financial barriers their overall wellbeing will increase. The following illustrative quotes help to qualitatively express the barriers to resources and environmental/social supports parents often encounter:

*[When my daughter was diagnosed with a disability] no list of resources was given. I did everything on my own to find her all of the services she required... There is no financial aid for the mountains of fees for her services because I am employed and make a fair wage. None of her cochlear implant needs, speech therapy, etc. are covered by insurance [because they are] all deemed elective. A representative from the insurance company actually stated, "Well she could just be deaf." Financially we are struggling, but I am trying to provide her with a good auditory and speech foundation and would sell my vital organs if that's what it would take.*

*It's hard enough to deal with all the daily demands of life with a child with special needs without having to constantly fight for everything and make sure people are doing their job. Just dealing with her paperwork is an overwhelming job. We've had to fight to get syringes to administer medication...I could go on, but the primary difficulties are feeling isolated and attempting to get the equipment and therapies our daughter needs while managing the rest of life as well.*

**Appraisal of Growth and Threat.** Of the two appraisal variables included in this study, appraisal of threat had the greatest direct contribution to parent wellbeing ( $\beta = -.37, p = .002$ ). This finding suggests that perceptions of potential harm to different aspects of life due to the challenges and responsibilities associated with raising a child with a disability are associated with lower wellbeing. The following statements from two parents further illustrate the perception that other areas of life can be threatened or harmed due to challenges related to raising a child with a disability.

*Because of her disabilities it is harder to get out...[we] can't do anything on the spur of the moment, [ we] have to make extensive plans just to go for an outing*

*[because of the] feeding tube [and problems related to positioning and mobility]. She has to take treatments for her immune system so we are confined to home during flu seasons...She is going to be 21 before long and will lose her nursing services [even though] she still has all the same disabilities... I can't just run out to the mailbox or to do yard work, someone has to be with her 24/7.*

*We have moved three times, once across the country, to access an appropriate educational placement for my daughter. It can be difficult to balance my daughter's social activities with my other daughter [without a disability]...They attend different school districts.*

To a lesser extent, appraisal of positive growth also significantly contributed to parent wellbeing ( $\beta = .19, p = .04$ ) indicating that parents who perceive more positive growth have improved overall wellbeing. The following statements illustrate how many parents grow through their parenting experiences:

*Even with all the challenges we face, my son is a joy and a blessing. I learn so much from him on a daily basis. I have learned to look at life from his black and white perspective and learned to let go of things that really don't matter in the big picture. If someone told me that he could be cured of autism today, I'm not sure I would take the deal.*

*[Raising a child with a disability has] strengthened my advocacy for all kinds of social justice, boundless opportunities to appreciate patience, very rewarding, overflowing, [and] exploding feelings of joy experienced only by parents who see kids achieve small things when they try REALLY hard. [I] never knew I had so much compassion inside me, amazing to see how my children could impact community members positively and watching their purpose unfold is a miracle. Our immediate family bond is immeasurable because of their differences and challenges.*

As previously mentioned, appraisal of threat and growth can occur simultaneously in the parent's lives (Taunt & Hastings, 2002). The following quotes from two parents illustrate how they can perceive significant threats to certain aspects of their lives while at the same time perceive positive benefits.

*Mostly our challenges stem from the financial aspect. I have to decide whether my mortgage or my child's needs are more important many times throughout the*

*year. This perpetuates the stress levels in our home. I can't work a second job because no one is available to care for my child that is qualified to handle her special needs. I do feel ostracized in the community to an extent because unless you have a special needs child it is difficult to grasp the constraints placed on you. That said I love my daughter with all my heart and would continue living stressed out until my dying day to have her achieve all the successes waiting for her! My daughter's accomplishments are the joys of my life. Each day I see progress, [she is] a blessing and not an imperfection. She is perfect in my eyes. She simply amazes me.*

*Our financial situation is very bad; if I didn't have my parent's help I couldn't make it... [People in my neighborhood] don't interact with us and they look at us with pity. I have lost great connections with my friends and long distance family members because I don't have time to interact with them... I could really go on and on with all the problems, but seeing my daughter's beautiful smile and her great and happy spirit is what keeps me going and doesn't let me fall apart, even through all these issues I'm very blessed for having her. She's the best example of human accomplishment I have ever seen. I found my hero in a very small and young person, my daughter.*

Given their role in the model analyzed here, the appraisal variables also served as endogenous variables. Consequently, it is important to mention the direct effects disability severity, problem solving, and resources and environmental/social supports had on the appraisal variables. Both appraisal of threat ( $\beta = .18, p = .03$ ) and appraisal of growth ( $\beta = .24, p = .02$ ) were significantly predicted by disability severity. This suggests that being a parent of a child with more functional impairment is related to more perceptions of both threat and growth in their lives. Problem solving also significantly predicted the appraisal of threat ( $\beta = -.26, p = .001$ ), but not the appraisal of growth ( $\beta = .13, p = .16$ ). This indicates that better parental problem solving abilities is associated with fewer perceived threats, but is not necessarily associated with the perception of more positive growth. Similar to problem solving, resources and environmental/social supports significantly contributed to appraisals of threat ( $\beta = -.54, p = .000$ ) but did not

significantly contribute to appraisals of growth ( $\beta = -.02, p = .86$ ) suggesting that higher reported levels of resources and environmental/social supports were associated with fewer threat appraisals, but having more resources and supports did not contribute to the perception of positive growth.

In addition to having a direct influence on parent wellbeing, the appraisal variables were also tested for their potential mediating influence on parent wellbeing. In this regard, findings were mixed. Neither appraisals of growth (indirect  $\beta = .05, p = .12$ ) nor appraisals of threat (indirect  $\beta = -.07, p = .09$ ) mediated the relationship between disability severity and parent wellbeing. Similarly, appraisal of growth (indirect  $\beta = -.003, p = .86$ ) did not mediate the relationship between resources and environmental/social supports and parent wellbeing. Appraisal of threat, however, did significantly mediate the relationship between parent wellbeing, resources and environmental/social supports (indirect  $\beta = .20, p = .005$ ), and problem solving ability (indirect  $\beta = .10, p = .02$ ) Overall, these results indicate that the total effect of resources and environmental/social supports on parent wellbeing is  $\beta = .54 (p = .000)$ , and the total effect of problem solving ability on parent wellbeing is  $\beta = .41 (p = .000)$ . Thus, parents reporting higher levels of resources and environmental social supports perceived less potential for threat due to the challenges related to raising a child with a disability, and, in turn, they reported significantly higher levels of overall wellbeing. Similarly, parents with better problem solving abilities perceived less threat and consequently reported higher levels of overall wellbeing.

*Controlling for Demographic Contributions.* Demographic variables were included in the analysis as predictors of the main independent variables (i.e., resources and environmental/social supports, growth, threat, and problem solving) in order to control for their contribution. The only significant demographic variable related to resources and environmental/social support was the parent's employment status ( $\beta = .19$ ,  $p = .04$ ) indicating that the number of hours worked per week is associated with increased access to information and resources and more environmental/social supports. Only parent age ( $\beta = .21$ ,  $p = .02$ ) significantly contributed to the parent's reported levels of problem solving ability suggesting that older parents tended to have better problem solving abilities. One mother mentioned how she had become better at confronting problems as she gained more experience while raising her child: "I have learned to put problems in perspective. I used to be so consumed with little problems, treating them like big ones. Not anymore; I look at the big picture...and I take extreme joy in simple things and small improvements." Third, the only demographic variable significantly related to the appraisal of threat was child age ( $\beta = .19$ ,  $p = .02$ ) suggesting that as children age parents perceive more potential for threat to important aspects of their lives. None of the demographic variables significantly contributed to the parent's appraisals of growth.

### **Discussion**

The experiences of informal caregivers, including parents raising children with disabilities, have become a growing area of interest over the past several years. Research, policy, and intervention efforts related to parents and families that have

children with disabilities have begun to reflect this growing interest and family-centered services are being promoted as optimal practice for enhancing the wellbeing of these families. This growing trend is especially important considering the irreplaceable influence parents have on the wellbeing of their children and family. Unfortunately, past research has often failed to examine the factors related to parent wellbeing in context. Failure to consider the parents experience in context has served to discount the complexity of their experiences as well as to perpetuate a negative view of raising a child with a disability. A significant strength of this study is its contextual approach to examining the wellbeing of parents. By so doing, this study supports other recent investigations which have evaluated the experiences of parents of children with disabilities using contextual models (e.g., Nachshen & Minnes, 2005; Zhu et al., 2006). This study also adds to previous research by simultaneously investigating the role of growth and threat appraisals in the path to parent wellbeing.

Overall, the results of this investigation have several important findings. First, the results of the SEM analysis in this study indicate that the proposed model tested here is a useful way to contextually examine factors related to the wellbeing of parent's raising children with disabilities. Model fit was clearly achieved based on the results of each of the fit indices used in this study. Moreover, the overall model accounted for the majority of the variance in the main endogenous variable, parent wellbeing.

Second, consistent with other investigations (e.g., Davis et al., 2009; Dunst, Leet, & Trivette, 1988), resources and environmental/social supports contributed the most to parent wellbeing. These findings provide further evidence for the importance of the



person-environment match (Resch et al., 2010) and suggest that parents who have sufficient access to information and services, encounter less financial barriers, and feel included within their surrounding community will have higher levels of overall wellbeing. Importantly, the total effect of resources and environmental/social supports on parent wellbeing was even greater when accounting for the mediating role of the parent's appraisals of threat.

Third, the non-significant relationship between child disability severity and parent wellbeing indicates that the child's overall level of functioning may not be the greatest predictor of parent wellbeing. Other individual characteristics, however, did significantly contribute to parent wellbeing (i.e., parent problem solving ability, child age, number of children, and household income). Parents with better problem solving abilities reported higher levels of wellbeing which is consistent with previous research demonstrating that good problem solving is related to more positive health outcomes (e.g., depression; Nezu, Wilkins, & Nezu, 2004). The positive relationship between age of the child and parent wellbeing has several possible explanations. As the child becomes older parents may adjust to their new, unique parenting roles. Moreover, as the child ages parents become more familiar with navigating the service delivery systems they need for their child and family, and their child may become more independent in performing daily living activities lessening the need for daily assistance by parents. The negative relationship between number of children and wellbeing may be a result of increased demand on the parent's time and mental/physical resources as well as the concern over the needs of the other children. The positive relationship between

household income and parent wellbeing may seem self-evident: increased income is related to more financial security which, in turn, may be associated with more availability of resources and supports. Notably, however, the correlation between household income and resources and environmental/social supports was not significant and the SEM analysis further showed that access to resources and environmental/social supports was not predicted by household income. Thus, it is unclear based on these findings why household income is associated with higher levels of parent wellbeing. One possible explanation is that income is an important factor in determining a family's socioeconomic status (SES) and people with higher SES are often afforded greater opportunities in many areas in life while also being less likely to experience many barriers (e.g., access to healthcare) that could affect wellbeing.

Fourth, regarding the role of threat and growth appraisals, results of this study are mixed. Appraisals of threat and growth clearly have a significant direct effect on parent wellbeing, but their indirect effect is less profound. In terms of the direct effect, parents who perceived more threats to important areas of their lives had lower levels of wellbeing. Conversely, parents perceiving positive growth from raising a child with a disability had higher levels of wellbeing. The greatest contributors to appraisals of threat in this study were resources and environmental/social supports and problem solving ability. Parents reporting more access to resources and environmental/social supports perceived much lower levels of threat compared to parents reporting insufficient access to resources and supports. Moreover, parents able to effectively solve problems in everyday life are also able to perceive fewer threats to important areas of their lives. This

is consistent with the notion that effective problem solving can eliminate or reduce perceived threats or barriers in one's life. For parents of children that had disabilities which significantly limited or impeded their ability to perform basic ADLs, they also reported more perceived threat and more perceived growth. Individuals often experience growth in the face of challenges and not simply despite of them. Consequently, it may not be surprising that parents raising children with more severe disabilities also reported more perceived growth as the challenges they encounter may also potentially serve to strengthen them. Regarding the mediating role appraisals of threat and growth have in this model, only two significant indirect relationships were discovered. In addition to having a direct effect on parent wellbeing, resources and environmental/social supports had a significant, indirect relationship with parent wellbeing by way of threat appraisals. Thus, parents reporting more access to information, services, social supports were less likely to perceive potential for harm in important areas of life. This finding, in turn, was associated with increased levels of overall wellbeing. Appraisals of threat also mediated the relationship between problem solving and parent wellbeing suggesting that parents with better problem solving abilities perceived fewer threats and, perhaps as a result, they reported higher levels of wellbeing.

## STUDY TWO

According to the National Institute of Mental Health (2010) 6.7% of the adult U.S. population has major depressive disorder. Certain groups within the U.S., however, are at increased risk for experiencing mental health problems such as major depression. One such group that may be at increased risk for major depression is parents raising children with disabilities. In general, extant research clearly demonstrates that parents raising children with disabilities are more likely to experience elevated levels of stress and, as a result, a decrease in quality of life (Browne & Bramston, 1998), but specific studies on more serious psychopathology such as major depression in this population subset are less clear.

Moreover, it should be noted that recent trends in research, policy, and intervention related to the experiences of families raising children with disabilities have attempted to emphasize a more positive outlook on their lives. Glidden (1993) asserted that the perception among many professionals working with parents raising children with disabilities is that these parents are maladjusted. This view is neither true nor helpful as many parents raising children with disabilities are, indeed, happy and psychologically well adjusted despite their unique and often stressful caregiving challenges. Nevertheless, compared to the larger population of parents, individuals raising children with disabilities encounter challenges that could put them at increased risk for mental/emotional health problems such as major depression. Thus, investigations which help to identify parents who are “at risk” for depression will enable policy makers,

educators, and other professionals to prevent and/or more effectively assist these parents before significant parent and family maladjustment occurs. Given the considerable influence parents have on the overall adjustment and health of their families, gaining such an understanding is an important endeavor.

Past studies have reported depression prevalence rates for parents raising children with disabilities to be between 35% and 53%, but problems with small samples sizes and differences in depression measurement methods must be considered when interpreting these findings (Olsson & Hwang, 2001). Although past findings generally show that parents raising children with disabilities are at increased risk for depression compared to other parents, Veisson (1999) points out that the results of published literature about depression in parents raising children with disabilities are often conflicting. For example, some research has demonstrated that, compared to parents of children without disabilities, parents of children with disabilities are more likely to be depressed, while other studies have found no difference between the two groups. For example, in one study of 187 mothers of children with intellectual disabilities the overall depression scores of the participants were generally low suggesting a more positive outlook for these parents (Glidden & Schoolcraft, 2003). Conversely, in a study of over 300 parents of children with and without disabilities, the parents raising children with disabilities were significantly more likely to have depressive symptoms (Veisson, 1999).

One significant shortcoming in many of these studies is their failure to clarify what factors make parents raising children with disabilities more at risk for depression. Glidden and Schoolcraft (2003) recommended that future studies examining depression

in parents raising children with disabilities measure multiple predictor variables simultaneously in order to more accurately capture the factors influencing depression risk status.

When investigating factors that influence the mental/emotional health of parents raising children with disabilities a starting point has often been individual characteristics of the parent, their family, and the child with the disability. For example, consistent with findings that women in general are more likely to have depression (NIMH, 2010), mothers raising children with disabilities are also more likely to endorse depressive symptoms (Bristol, Gallagher & Schopler, 1988). Additionally, one study about mothers raising children with disabilities found that mothers reporting less depression tended to have more education and higher income levels compared to mothers reporting more depression (Breslau, Staruch, & Mortimer, 1982). Some evidence also suggests that marital status, socioeconomic status (Olsson & Hwang, 2001), race, and geographic location (e.g., rural vs. non-rural; Darling & Gallagher, 2004) may be significantly associated with parent mental health. Given the scarcity of published literature about the relationship between these parent specific variables and depression (Olsson & Hwang, 2001), the relative strength of these relationships continues to be unknown.

Factors associated with the child's disability are also important to consider as evidence suggests they significantly influence parent depression status. Specifically, the type and severity of the child's disability and child behavior problems are the most commonly studied variables related to parent wellbeing. Some studies (e.g., Olsson & Hwang, 2001) have revealed that parents of children with autism report more depressive

symptoms than parents of children with intellectual disabilities. Using disability type as a reliable predictor variable may be somewhat limiting as significant variations in child functioning and behavior can exist within and between disability types. Levels of independent child functioning and behavior problems may prove more useful as determinants of parent wellbeing and past research has established more clearly this relationship (Floyd & Gallagher, 1997; Fournier, Davis, Patnaik, Elliott, Dyer, et al., 2010). Another common area of investigation when examining the mental/emotional health of parents raising children with disabilities is the role of environmental characteristics. Findings suggest that parents perceive socio-cultural and environmental constraints as more challenging than child-specific problems. The environmental variables that contribute to parent wellbeing are associated with financial barriers, community and social inclusion, family cohesion, and obtaining access to necessary information and services for their child and family (Green, 2007; Resch, 2010, Worcester et al., 2008).

Several additional variables should also be considered with investigating depression risk for parents raising children with disabilities. First, it stands to reason that the parents feeling supported at home will be less likely to report serious mental health problems (i.e., depression). Such an assertion deserves more attention and past findings have provided initial support for the relationship between depression and family satisfaction in parents raising children with disabilities. Glidden and Floyd (1997) discovered that family accord and marital satisfaction were significantly correlated with scores on a depression inventory in a study about parents of children with disabilities.

Second, Hastings (2002) recommended that future studies of the wellbeing of parents raising children with disabilities focus on appraisal variables such as parent beliefs. Two such parent appraisals (threat and positive growth) may be particularly powerful variables related to parent mental/emotional health. For example, one study found that parent stress appraisals were more predictive of depression than child disability severity (Kronenberger & Thompson, 1992). Moreover, mounting evidence demonstrates that appraisals of growth and benefit are also important to parent mental/emotional health (Taunt & Hastings, 2002) and parents perceiving more positive growth due to their parenting responsibilities may be less likely to experience significant mental health problems such as depression. Third, many researchers (e.g., Dreer, Elliott, Fletcher & Swanson, 2005; Dreer, Elliott, Shewchuck, Berry, & Rivera, 2007; Rivera, Elliott, Berry, Grant, & Oswald, 2007) have investigated the role problem solving ability has on the mental health of individuals caring for adults with various types of disabling conditions (i.e., traumatic brain injury, stroke, dementia, and spinal cord injury). Their findings provide strong evidence that ineffective problem solving abilities are significantly related to caregiver depression status. Unfortunately, problem solving has been largely neglected in research about parents raising children with disabilities. Given the promise this area of inquiry potentially provides, parental problem solving ability merits further attention. Fourth, the link between physical health and mental health is well established. Thus, any attempt to examine determinants of depression in parents raising children with disabilities should also account for the parent's general physical condition.



Study two was designed to examine parents raising children with disabilities who are considered at risk for depression. It was expected that, after controlling for individual characteristics of the parent and the child, differences on measured variables such as physical health, family satisfaction, problem solving ability, appraisals of threat and positive growth, and environmental/social supports would distinguish those parents at risk for depression from those parents not at risk for depression.

### **Data Analysis**

#### ***Study Two Variables***

Study two included the following variables in its analysis as predictor variables: Parent demographic data (i.e., education level, employment status, annual household income, and parent age); activities of daily living and urinary/bowel continence (PCAF); appraisals of growth (PTGI) and threat (Threat scale); resources and environmental/social supports (RESS-Q); problem solving abilities (SPSI-R-10); physical health (PCS scale from the SF12); and family satisfaction (FSS).

The outcome variable for this study was the parent's depression status. As previously mentioned, past studies on depression levels in this population have used many different types of depression measures. In an attempt to ameliorate this problem, the PHQ9, a measure based on the Diagnostic and Statistical Manual IV (American Psychiatric Association, 2000) criteria of major depression, was used as the dependent variable. Given the type of statistical analysis used in this study, depression status was coded dichotomously with participants scoring  $\geq 10$  being coded as one and participants scoring from 0-9 receiving a code of zero.

In order to provide clarity and direction to the study results, the data analyses were informed by empirically supported scientific theories. As will be described hereafter, the analytic model chosen for this study specifically reflects these expectations. Basing this study design and analysis on the extant empirical findings mentioned previously should provide a clearer interpretation of the findings as well as more valid results (Hoyt, Imel, & Chan, 2008).

Preliminary data analysis steps included descriptive statistics, tests of group differences and zero order correlations of all variables included in the analysis. One hundred and ten participants were included in study two's analysis. As previously mentioned, this study's design and analysis is based on past empirical findings with the specific purpose of identifying variables that best predict depression in a sample of parents raising children with disabilities. To systematically test this purpose a four block hierarchical logistic regression (HLR) analysis was conducted. HLR is essentially a series of regression analyses where additional sets of predictor variables are added at different blocks in order to determine if each new set of predictor variables account for significant variance in the criterion variable while still including previously entered sets in the model (Hoyt et al., 2008). HLR models should be informed by past empirical findings and scientific theory. Optimal use of HLR occurs when independent variables (IV) belonging to similar categories or measuring similar constructs are included in the analysis as sets of IVs, instead of being entered as individual IVs as would be done in typical regression approaches. By so doing, HLR analysis calculates how much variance in the dependent variable (DV) is explained by each block. A regression coefficient for

each individual variable is also calculated in order to measure each individual variable's distinct contribution (Hoyt et al., 2008).

Measured IVs for this study were chosen based on known empirical evidence of their relationship to depression in populations similar to that studied here. IVs were then combined into sets based on belonging to categories that made theoretical sense for this study. Thus, in set one depression status was regressed on parent demographic variables to control for their contribution. The second set consisted of variables related to the child's disability (PCAF ADL and continence scales). Notably, because child age and parent age were highly correlated ( $r = .72$ ) child age was not included in the analysis in order to avoid problems with multicollinearity. Set three consisted of the RESSQ, SPSI-R-10, PTGI and Threat measures. Although each of these variables is measuring a distinct construct, they were included in the same category because each one was measuring some type of psychosocial factor. Finally, set four consisted of two variables measuring general wellbeing or satisfaction, the PCS and the FSS.

## **Results**

Participants were dichotomously categorized as being at risk for depression or not at risk for depression. The cut-off score for probable depression on the PHQ9 was  $\geq 10$ ; the established cut-point for moderate depression. Table 5 provides information by depression risk status on parent demographic and child characteristic variables, as well as all other predictor variables included in this study. Chi-square tests performed for parent education level, annual household income, marital status, and disability type revealed no significant differences between the two risk status groups on these variables.

Table 5

*Sample Statistics and p Values for Independent Samples T-tests*

	Depression Risk				<i>Absolute Mean Difference</i>	<i>t-test p-values</i>
	Minimal Risk (n=91)		At Risk (n=19)			
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
<i>Demographics</i>						
Parent Age	45.7	8.4	45.3	9.8	.4	.87
Parent Education Level	3.7	.56	3.6	.50	.1	.82
Household Income	3.5	1.2	3.1	1.2	.4	.18
Employment Status	2.0	.9	2.2	.9	.2	.63
<i>Disability Characteristics</i>						
ADLs	14.5	13.5	16.4	17.2	1.9	.67
Urinary/Bowel Continence	2.7	4.0	3.5	4.0	.8	.47
<i>Psychosocial Variables</i>						
Threat Appraisals	19.3	9.9	27.3	10.6	8.0	.002**
Growth Appraisals	61.5	22.0	58.0	21.0	3.5	.48
Environmental/Social Supports	35.0	9.0	33.5	8.2	1.5	.49
Problem Solving	31.0	5.1	28.1	5.0	2.9	.04*
<i>Parent Wellbeing</i>						
Family Satisfaction	50.0	11.0	40.2	9.0	9.8	.001***
Physical Health	53.0	9.1	44.0	14.1	9.0	.01**

*Note.* \* = significant difference of less than .05, \*\* = significant difference of less than .01,

\*\*\* = significant difference of less than .001.

Independent samples t-test were also conducted for each continuous predictor variable. No mean differences were found between the two groups on average parent age or any of the child's disability variables. Significant differences, however, were found on several other predictor variables. The groups significantly differed on their report of threat appraisals with the "at risk" group reporting more threats. The "at risk" group also reported significantly less problem solving ability, less family satisfaction, and lower

overall physical health. The two groups did not differ on their report of access to resources and environmental/social supports or appraisals of positive growth.

Hierarchical logistic regression analysis was conducted using SPSS (2007) as a way to predict which participants were at risk for depression (see Table 6). Due to missing data on a small number of surveys, 86% ( $n = 94$ ) of the participants were included in the logistic regression analysis. Eighteen (19.1%) of the parents included in this part of the analysis had depression scores at or above 10 on the PHQ9. Accordingly, the HLR cut value for depression classification was set at .191. Predictors were entered into four blocks. Parent demographic variables were entered into block one to control for their contribution. The contribution of the demographic variables was not significant ( $\chi^2(4) = 2.87$ ) and did not provide predictive power beyond that of the null model. In block two the contribution of the child disability characteristics were entered. Similar to block one, these variables, did not contribute to prediction beyond the null model,  $\chi^2(2) = .44$ , *ns*. Four variables (SPSI-R-10, RESSQ, Threat, and PTGI) were inserted into block three. The addition of these variables to the model significantly improved the model's predictive ability above and beyond the null model,  $\chi^2(4) = 14.92$ ,  $p < .01$ . The parents' appraisal of threat was significantly contributory ( $\beta = .110$ ; odds ratio = 1.12; Wald [1] = 7.07,  $p < .01$ ) to block three. This means that with each unit increase in appraisals of threat, parents were 12% more likely to be at risk for depression. The SPSI-R-10, RESSQ, and PTGI did not significantly contribute to block three. These findings suggest that parents reporting more threat appraisals were at significantly greater risk for

Table 6

*Hierarchical Logistic Regression Predicting Depression Risk Status*

	$\beta$	S.E.	Wald	<i>df</i>	<i>p</i>	Odds Ratio	95% C.I. for Odds Ratio	
							Lower	Upper
<i>Demographics</i>								
Parent Age	-0.05	0.06	0.79	1	.38	.95	.86	1.06
Parent Education Level	.94	0.87	1.16	1	.28	.39	.07	2.16
Household Income	-0.16	0.40	0.16	1	.69	.85	.39	1.85
Employment Status	0.13	0.42	0.09	1	.76	1.13	.50	2.56
<i>Disability Characteristics</i>								
ADLs	0.05	0.03	2.21	1	.14	1.05	.98	1.12
Urinary/Bowel Continence	-0.14	0.12	1.33	1	.25	.87	.69	1.10
<i>Psychosocial Variables</i>								
Threat Appraisals	0.11	0.05	4.78	1	.03*	1.12	1.01	1.23
Growth Appraisals	-0.01	0.16	0.22	1	.64	.99	.96	1.03
Environmental/Social Supports	0.11	0.06	2.99	1	.08	1.11	.99	1.25
Problem Solving	-0.05	0.08	0.30	1	.58	.96	.81	1.12
<i>Parent Wellbeing</i>								
Family Satisfaction	-0.13	0.06	5.71	1	.02*	.88	.79	.98
Physical Health	-0.06	0.03	4.11	1	.04*	.94	.86	1.0
<i>Constant</i>	4.99	4.88	1.03		.31			

Note. \* = significant at  $p < .05$

depression. Based on the Cox and Snell, and Nagelkerke pseudo *R*-Squared estimates, the variables entered into block three accounted for 14.1% to 22.8% of the variance in the participants risk status for depression.

The FSS and PCS were entered into the fourth and final block of the equation. Overall, this final block ( $\chi^2 [2] = 12.56, p < .01$ ) significantly contributed to the prediction of depression risk status. Both the FSS ( $\beta = -.131$ ; odds ratio = .877; Wald [1] = 5.77,  $p < .01$ ) and PCS ( $\beta = -.062$ ; odds ratio = .940; Wald [1] = 4.11,  $p < .05$ ) independently and significantly contributed to the overall model and to the prediction of depression risk status in block four. Thus, for each unit decrease in the parent's reported family satisfaction, participants were 12.3% more likely to be at risk for depression. Similarly, for each unit decrease in the parents PCS score, they were 6% more likely to be at risk for depression.

Table 7

*Classification Matrix for Prediction of Depression Risk Status*

Observed Group	Predicted Group		% Accurate
	Low Risk	High Risk	
Low Risk	58	18	76.3%
High Risk	3	15	83.3%
	Total Percent Accuracy		77.7%

The pseudo *R*-Squared values for this final block ranged from 10.3% to 16.5%, and, overall, the complete model was statistically significant ( $\chi^2 [12] = 30.79; p < .01$ )

accounting for an estimated 27.9% to 44.8% of the variance in depression status in this particular sample of participants. The Hosmer and Lemeshow Test provided further evidence of good model fit ( $\chi^2 [8] = 4.01; p = .86$ ). Moreover, prediction accuracy for depression status using this model was 76.3% for the Minimal Risk group, 83.3% for the At Risk group, and 77.7 for the entire sample (see Table 7).

### **Discussion**

The purpose of this study was to identify possible predictors of depression risk status in a sample of parents raising children with disabilities using an analytical model supported by past research and theory. To a large extent this purpose was met (despite some limitations that will be explained hereafter). Several important findings deserve further discussion. First, the percentage of parents identified as being at risk for depression in this group (19.1%) was much lower than the range of 35% to 53% found in past research on similar populations (Olsson & Hwang, 2001), but nearly three times more than the average for the overall U.S. population (based on the 6.7% prevalence rate reported by the NIMH, 2010). On the one hand, these data indicate that parents raising children with disabilities are likely not as psychologically maladjusted as some studies have shown. Conversely, these parents may be at higher risk for depression than the general public. It is worth noting, however, that parents participating in this study belong to a non-clinical population and, therefore, the rates of depression among this community-residing sample may not be as high as a clinical sample of adults.

Another possible explanation for the lower depression prevalence rate found in this study compared to other studies is that the PHQ9 is strictly modeled after the DSM-



IV depression criteria. Although not a diagnostic tool per se, the PHQ9 was designed to specifically detect the presence of possible mood psychopathology (i.e., clinical depression) and not simply general emotional maladjustment (i.e., mild anxiety or stress). Past studies provide support for this explanation. In a similar study about family caregivers Dreer et al. (2007) reported a similarly low (15.7%) depression prevalence rate in their sample. Their study also used a more conservative measure of depression status and they hypothesized that many studies examining similar populations have used measures that have much more liberal depression criteria. As a result, past studies of parents raising children with a disability may not have actually been measuring clinical depression, but rather, a non-psychopathological emotional problem. This lack of continuity in depression measurement could be one significant reason why depression prevalence rates have varied so widely.

A second important finding in this study is that the two groups of parents did not significantly differ on any of the demographic variables in any of the mean difference analysis. Thus, based on these findings, demographic variables may not be the best indicators of parent distress. Third, findings also suggest that disability characteristics of the child do not sufficiently distinguish between the two depression risk groups. Consequently, using child disability characteristics to make inferences about possible causes of parent depression may not be fruitful. In the past, such inferences may have contributed to a negative view of having a child with a disability. Evidence continues to suggest that parental maladjustment is often more associated with variables not related to

the child, but instead, to problems accessing information, resources, and environmental/social supports (Green, 2007; Resch et al., 2010, Worcester et al., 2006).

Fourth, these findings suggest parents at risk for depression had significantly worse global problem solving abilities and significantly higher threat appraisal levels than the parents not at risk for depression. Consequently, the “at risk” parents are probably more likely to struggle to maintain a positive orientation toward solving everyday problems, and to brainstorm problem solutions, generate alternatives, and implement effective problem solving plans. Moreover, the “at risk” parents may have negative beliefs and fears about the potential for harm posed by the challenges of raising a child with a disability. Threat appraisals were also significantly predictive of depression status in the HLR analysis, but problem solving ability did not predict depression status as it has done in other studies about informal caregivers of individuals with disabilities (e.g., Dreer et al., 2005; Dreer et al., 2007; Grant et al., 2004).

Fifth, these findings clearly indicate that the overall level of satisfaction with their home life is strongly related to parent emotional adjustment. Parents in the depression risk group were much more dissatisfied with their family situation than the parents not at risk for depression and family satisfaction was significantly contributory to the overall HLR model. Thus, family satisfaction is a potentially important variable related to parental emotional health. A few past studies have highlighted this important relationship, but the family side of having a child with a disability has traditionally been neglected in research (Ones et al., 2005). This is troubling because the unit of society most affected by having a child with a disability is the family and high satisfaction with

family functioning has been shown to be associated with increased coping and more positive appraisals (Failla & Jones, 1991). The marital relationship, in particular, may be especially important for positive adjustment. Friedrich (1979) found that marital satisfaction accounted for an impressive 79% of the variance related to coping behavior in a sample of parents raising children with disabilities.

Sixth, the parent's general level of physical health was significantly worse for parents raising children with disabilities. Additionally, physical health was a significant predictor of depression risk status for this sample. Consequently, it is clear in the sample studied here that parents at risk for depression also have significantly worse overall health than the other parents. Well established in the scientific literature is the relationship between physical health and emotional health and this significant relationship certainly holds true for parents raising children with disabilities. In fact, optimal physical functioning may be particularly important given the unique, and sometimes physically demanding, parenting responsibilities these parents have.

Finally, the results of the overall model predicted depression risk status with 83% accuracy. This prediction accuracy is less than a similarly conducted study by Grant et al. (2004), but greater than other similar studies (e.g., Dreer et al., 2005; Dreer, et al., 2007). Although additional variables not measured in this investigation likely contribute to depression risk status, these findings provide evidence that differences in specific areas put parents raising children with disabilities at risk for emotional maladjustment. Specifically, appraisals of threat, problem solving abilities, family

satisfaction, and physical health seem to be particularly important to parental emotional health when raising a child with a disability.

## **CONCLUSION: LIMITATIONS AND FUTURE DIRECTIONS**

In addition to the strengths and implications of these studies, several important limitations should also be mentioned. First, no data regarding child behavior were gathered. Fournier et al. (2010) found that child behavior problems, independent of the child's level of functional impairment, were related to caregiver requests of personal care services. Therefore, when analyzing relationships similar to those examined here, future studies should address this shortcoming. Importantly, however, not including information about child behavior should not necessarily negate the importance of these findings, particularly in light of recent evidence suggesting that lower levels of parent wellbeing may actually be more predictive of subsequent child behavior problems than vice-versa (Osborne & Reed, 2009).

Second, nearly all of the participants were mothers and, therefore, the results of this investigation may not generalize to the experience of fathers or other family caregivers such as grandparents. Future studies should explicitly target these other groups of informal caregivers of children with disabilities as they are an understudied population. However, having a sample of mostly mothers does not limit the usefulness of these findings because mothers of children with disabilities typically provide most of their care even when they are employed (Bristol et al., 1988). Consequently, mothers are likely most able to give accurate perceptions of the stressful life events their family encounters (Uphold & Strickland, 1989). Third, most of the sample was white/European American, spoke English, lived in non-rural areas, and had a college education.

Consequently, generalizing these findings beyond these parameters should be done with caution. Notably, heterogeneity was achieved in other areas (i.e., parent employment status, parent age, and household income). Fourth, given the cross-sectional nature of this study, no statements about causality can be made. The analytical model used here found several predictors of wellbeing and depression status in this sample of parents, but prediction in this model should not be confused with causality in the general population of parents raising children with disabilities. Future studies should address the overlap between these variables and the potentially reciprocal relationship between them. Fifth, future studies will be enhanced by including a comparison group consisting of parents raising children without any type of disability.

Regarding study two, the cut-off of  $\geq 10$  on the PHQ9 to determine depression risk status for this sample may be viewed as a liberal depression cut-off point. Notably, however, past studies have demonstrated that using the  $\geq 10$  cut-off point is equally useful as a more sophisticated PHQ9 scoring algorithm (Gilbody, Richards, Brealey, & Hewitt, 2007) and the  $\geq 10$  cut-off point has been proven to have better diagnostic performance compared to other commonly used depression measures (Williams, Noel, Cordes, Ramirez, & Pignone, 2002). Moreover, individuals with scores at or above the standard  $\geq 10$  cut-off point have been shown to be significantly more likely to be diagnosed with depression following a more in-depth clinical interview by a mental health professional than those scoring below the cut-off (Kroenke et al., 2001). Gilbody et al. (2007) also found that for a community-based (non-clinical) sample such as that studied here, an even lower cut-off score ( $\geq 9$ ) may be most appropriate.

Despite these limitations, the findings of this study are promising for researchers, policy makers, educators, clinicians, and families raising children with disabilities.

Research that builds on these findings will continue to uncover possible predictors of overall parent wellbeing and depression risk status that will, in turn, inform health and education policy decisions aimed at helping these families. Furthermore, clinical professionals (i.e., psychologists, social workers, physicians, nurses, etc.) and educators working with parents raising children with disabilities will be more equipped to identify those parents at risk for more significant psychological maladjustment. By understanding these risk factors our ability to prevent and/or intervene when maladjustment does occur will be greatly enhanced.

Future research that examines parent wellbeing using a theoretically based model is particularly recommended. Using a model to organize and understand outcomes is useful because it can not only explain aspects of certain processes, but it can also specifically inform policies and interventions (Dunn & Elliott, 2008). Congruent with this assertion, results of this study are informative in several ways.

As previously discussed, effective problem solving has been shown to be associated with better health outcomes and recent findings also suggest that informal caregivers benefit from problem solving training (Elliott et al., 2009; Rivera et al., 2008). This study provides support for these findings as parents with better problem solving abilities reported fewer threat appraisals as well as increased levels of wellbeing. Thus, a potentially significant area of intervention for professionals working with parent of children with disabilities is to provide problem solving training. Problem solving

training specifically tailored to address the challenges commonly encountered by parents similar to those in this study may be especially useful.

These findings provide considerable evidence for the important role of appraisals in relation to parent wellbeing. Studies concerning raising a child with a disability have often been permeated by negative content and tone which “has emphasized stress and burden, incapacity and dependency, leading to negative stereotyping of families...” (Grant, 2007, p.15). Recently much research has begun to reveal that this pessimistic view of parenting a child with a disability is not only limiting, but also misleading as emerging evidence suggests that raising a child with a disability is probably as joyous as raising a child without a disability (Taunt & Hastings, 2002; Wilgosh, Nota, Scorgie & Salvatore, 2004). This study further supports these findings and individuals working with or doing research about parents raising children with disability should consider the potential for positive growth and benefit finding many families experience. Negative appraisal processes should also be considered in future research as these findings clearly suggest that maladaptive appraisals play an important role in parent wellbeing. In particular, intervention efforts will benefit from attending to the presence of threat appraisals as they appear to be particularly associated with the wellbeing of parents raising children with disabilities.

Many others (e.g., Beckman, 2002; Resch et al., 2010) have highlighted the importance of conducting research, creating policies, and promoting interventions that are family-centered when assisting families that have children with disabilities. The findings of this study related to the significant relationship between resources and



environmental/social supports, appraisal of threat, and parent wellbeing provide further evidence of the value in supporting parents and their families, and not only the child with the disability. Other studies have yielded similar results (e.g., Nachshen & Minnes, 2005), but recent investigations (e.g., Davis et al., 2009) continue to illustrate that parents often struggle to obtain access to supports and services needed by their family. Given the mounting evidence that suggests parent wellbeing is enhanced as they have better access to resources and environmental/supports, policy makers, educators, clinicians, and researchers should promote and practice family-centered services.

## REFERENCES

- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders-text revision* (4<sup>th</sup> ed.). Washington, DC.
- Anderson, W. P., & Lopez-Baez, S. I. (2008). Measuring growth with the posttraumatic growth inventory. *Measurement and Evaluation in Counseling and Development*, *40*, 215-227.
- Arno, P.S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs*, *18*, 182-188.
- Baldwin, K. Brown, R. T., Milan, M. A. (1995). Predictors of stress in caregivers of attention deficit hyperactivity disordered children. *The American Journal of Family Therapy*, *23*, 149-160.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*, 702-714.
- Beckman, P. J. (2002). Providing family-centered services. In M. Batshaw (Ed.) *A medical primer* (pp. 683-691). Baltimore, MD: Paul H. Brookes Publishing Company.
- Blackburn, C. & Read, J. (2005). Using the internet? The experiences of parents of disabled children. *Child: Care, Health & Development*, *31*, 507-515.
- Boyle, C. A., Decoufle, P. & Yeargin-Allsopp, M. (1994). Prevalence and health impact of developmental disabilities in US children. *Pediatrics*, *93*, 399-403.

- Breslau, N., Staruch, K. S., & Mortimer, E. A. (1982). Psychological distress in mothers of disabled children. *American Journal of Diseases of Children, 136*, 68res2-686.
- Bristol, M., Gallagher, J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24*, 441-451.
- Browne, G. & Bramston, P. (1998). Stress and quality of life in the parents of young people with intellectual disabilities. *Journal of Psychiatric and Mental Health Nursing, 5*, 415-421.
- Byrne, B. M. (2001). *Structural Equation Modeling with AMOS: Basic Concepts, Applications and Programming*. Mahwah, NJ, Lawrence Erlbaum Associates.
- Chamberlin, J. (2009,). Goodheart is APA's next president. *Monitor on Psychology, 40*, 68-69.
- Chang, E. C., D'Zurilla, T. J., & Sanna, L. J., (2004). Social problem solving for the real world. In E. C. Chang, T. J. D'Zurilla, & L. J. Sanna (Eds.), *Social problem solving: Theory, research, and practice* (pp. 3-7). Washington, DC: American Psychological Association.
- Chwalisz, K. (1992). Perceived stress and caregiver burden after brain injury: A theoretical integration. *Rehabilitation Psychology, 37*, 289-203.
- Darling, S. M., & Gallagher, P. A. (2004). Needs of and supports for African American and European American caregivers of young children with special needs in urban and rural settings. *Topics in Early Childhood Special Education, 24*, 98-109.

- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2009). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health and Development, 36*, 63-73.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment, 49*, 71-75.
- Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Hollander Feldman, P., Levine C., & Gould, D.(2002). Challenged to care: Informal caregivers in a changing health system. *Health Affairs, 21*, 222-231.
- Dreer, L. E., Berry, J., Rivera, P. Snow, M., Elliott, T. R., Miller D., & Little, T. D. (2009). Efficient assessment of social problem-solving abilities in medical and rehabilitation settings: A rasch analysis of the social problem-solving inventory-revised. *Journal of Clinical Psychology, 65*, 653-669.
- Dreer, L. E., Elliott, T. R., Fletcher, D. C., & Swanson, M. (2005). Social problem-solving abilities and psychological adjustment of persons in low vision rehabilitation. *Rehabilitation Psychology, 50*, 232-238.
- Dreer, L. E., Elliott, T. R., Shewchuck, R., Berry, J. W., & Rivera, P. (2007). Family caregivers of persons with spinal cord injury: Predicting caregivers at risk for probable depression. *Rehabilitation Psychology, 52*, 351-357.
- Dunn, D. S. & Elliott, T. R. (2008). The place and promise of theory in rehabilitation psychology research. *Rehabilitation Psychology, 53*, 254-267.

- Dunst, C. J., Leet, H. E., & Trivetter, C. M. (1988). Family resources, personal wellbeing, and early intervention. *The Journal of Special Education, 22*, 108-116.
- Elliott, T. R., Berry, J. W. & Grant, J. S. (2009). Problem-solving training for family caregivers of women with disabilities: A randomized clinical trial. *Behavior Research and Therapy, 47*, 548-558.
- Elliott, T. R., & Mullins, L. L. (2004). Counseling families and children with disabilities. In D. Atkinson & G. Hackett (Eds.), *Counseling diverse populations, (3<sup>rd</sup> Ed., pp. 151-170)*. New York: McGraw-Hill.
- Elliott, T. R. & Warren, A. M. (2007). Why psychology is important in rehabilitation. In P. Kennedy (Ed.), *Psychological Management of Physical Disabilities* (pp. 16-39). New York: Routledge.
- Failla, S. & Jones, L. C. (1991). Families of children with developmental disabilities: An examination of family hardiness. *Research in Nursing and Health, 14*, 41-50.
- Feldman, M., McDonald, L. Serbin, L., Stack, D., Secco, M. L., & Yu, C. T. (2007). Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research, 51*, 606-619.
- Floyd, F. J. & Gallagher, E. M, (1997). Parental stress, care demands, and the use of support services for school-age children with disabilities and behavior problems. *Family Relations, 46*, 359-371.

- Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology*, *50*, 992-1003.
- Fournier, C. J., Davis, M., Patnaik, A., Elliott, T. R., Dyer, J. & Phillips, C. D. (2010). Modeling caregivers' perceptions of children's need for formal care: The role of physical function, intellectual disability level, and behavior problems. *Disability and Health Journal*, *3*, 213-221.
- Freedman, R.I. & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health and Social Work*, *25*, 59-68.
- Friedrich, W. N. (1979). Predictors of the coping behavior of mothers of handicapped children. *Journal of Consulting and Clinical Psychology*, *6*, 1140-1141.
- Fujiura, G. T., & Yamaki, K. (2000). Trends in demography of childhood poverty and disability. *Exceptional Children*. *66*, 187-199.
- Gaugler, J., Kane, R., & Langlois, J. (2000). Assessment of family caregivers of older adults. In R. Kane & R. Kane (Eds.), *Assessing older persons: Measures, meaning, and practical applications* (pp. 320-359). New York: Oxford University Press.
- Gilbody, S., Richards, D., Brealey, S., & Hewitt, C. (2007). Screening for depression in medical settings with the Patient Health Questionnaire (PHQ): A diagnostic meta-analysis. *Journal of General Internal Medicine*, *22*, 1596-1602.

- Glidden, L. M., (1993). What we do not know about families with children who have developmental disabilities: Questionnaire on resources and stress as a case study. *American Journal of Mental Retardation, 97*, 481-495.
- Glidden, L. M. & Floyd, F. J. (1997). Disaggregating parental depression and family stress in assessing families of children with developmental disabilities: A multisample analysis. *American Journal of Mental Retardation, 102*, 250-266.
- Glidden, L. M. & Schoolcraft, S. A. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research, 47*, 250-263.
- Grant, G. (2007). Invisible contributions in families with children and adults with intellectual disabilities. *Canadian Journal of Aging, 26*, 15-26.
- Grant, J. S., Weaver, M., Elliott, T. R. Bartolucci, A., & Giger, J. N. (2004). Family caregivers of stroke survivors: Characteristics of caregivers at risk for depression. *Rehabilitation Psychology, 49*, 172-179.
- Green, S. E. (2003). "What do you mean 'what's wrong with her?'": Stigma and the lives of families of children with disabilities. *Social Science and Medicine, 57*, 1361-1374.
- Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64*, 150-163.
- Hassall, R. & Rose, J. (2005). Parent cognitions and adaptation to the demands of caring for a child with an intellectual disability: A review of the literature and

- implications for clinical interventions. *Behavioural and Cognitive Psychotherapy*, 33, 71-88.
- Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability*, 27, 149-160.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107, 106-117.
- Hawes, C., Phillips, C., Morris, J., Mor, V., & Fries, B. (1997). The impact of the RAI on indicators of process quality. *Journal of the American Geriatrics Society*, 45, 977-985.
- Hoyt, W. T., Imel, Z. E., & Chan, F. (2008). Multiple regression and correlation techniques: Recent controversies and best practices. *Rehabilitation Psychology*, 53, 321-339.
- Katerndahl, D. A. & Parchman, M. (2002). The ability of the stress process model to explain mental health outcomes. *Comprehensive Psychiatry*, 34, 351-360.
- Kazak, A. E. & Wilcox, B. L. (1984). The structure and function of social support networks in families with handicapped children. *American Journal of Community Psychology*, 12, 646-661.
- Kline, R.B. (2005). *Principles and practice of structural equation modeling* (2<sup>nd</sup> ed.). New York: Guilford.



- Kittleson, M. (1997). Determining effective follow-up of email surveys. *American Journal of Health Behavior, 21*, 193-196.
- Konrad, S. C. (2006). Posttraumatic growth in mothers of children with acquired disabilities. *Journal of Loss & Trauma, 11*, 101-113.
- Krauss, M. W., Wells, N. Gulley, S. & Anderson, B. (2001). Navigating systems of care: Results from a national survey of families of children with special health care needs. *Children's Services: Social Policy, Research, and Practice, 4*, 165-187.
- Kroenke, K., Spitzer, R. L. & Williams, J. B. W. (2001). Validity of a brief depression severity inventory. *Journal of General Internal Medicine, 16*, 606-613.
- Kronenberger, W. G. & Thompson, R. J. (1992) Medical stress, appraisal stress, and the psychological adjustment of mothers of children with myelomeningocele'. *Journal of Developmental and Behavioural Pediatrics, 13*, 405-411.
- Lollar, D. (2008). Rehabilitation psychology and public health: Commonalities, barriers, and bridges. *Rehabilitation Psychology, 53*, 122-127.
- Macias, M. M., Clifford, S. C., Saylor, C. F. & Kreh, S. M. (2001). Predictors of parenting stress in families of children with spina bifida. *Children's Health Care, 30*, 57-65.
- Macias, M. M., Roberts, K. M., Saylor, C. F. & Fussell, J. J. (2006). Toileting concerns, parenting stress, and behavior problems of children with special health care needs. *Clinical Pediatrics, 45*, 415-422.

- McCarthy, M. G., & Stough, L. M. (1999). The qualifying game: A search for services by individuals with disabilities. *Education and Training in Mental Retardation and Developmental Disabilities, 34*, 485-498.
- Minnes, P. M. (1988). Family stress associated with a developmentally handicapped child. *International Review of Research in Mental Retardation, 15*, 195-226.
- Morris, J. N., Fries, B. E., Carpenter, G. I. & Bernabei, R. (1996). The RAI-HC assessment tool: An international reliability trial. *The Gerontologist, 36 (Special Issue 1)*, 291.
- Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2006). The health of caregivers for children with disabilities: Caregivers perspectives. *Child: Care, Health and Development, 33*, 180-187.
- Muthén, L. K. & Muthén, B. O. (2010). *Mplus User's Guide* (6<sup>th</sup> ed.). Los Angeles, CA: Muthén & Muthén.
- Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research, 49*, 889-904.
- National Institute of Mental Health (2010). The numbers count: Mental disorders in America. Accessed June 16, 2010 at <http://www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml#MajorDepressive>.
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2002). When the caregiver needs care: The plight of the vulnerable

- caregivers. *American Journal of Public Health*, 92, 409-413.
- Newacheck, P. W., & Kim, S. E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 159, 10-17.
- Nezu, A. M., Wilkins, V. M., Nezu, C. M. (2004). Social problem solving, stress, and negative affect. In E. C. Chang, T. J. D’Zurilla, & L. J. Sanna (Eds.), *Social problem solving: Theory, research, and practice* (pp. 49-66). Washington, DC: American Psychological Association.
- Olson, D. H., & Wilson, M. (1982). Family inventories: Inventories used in a national survey of families across the family life cycle. In D. H. Olson, H. I. McCubbin, H. Barnes, A. Larsen, M. Muxen, & M. Wilson (Eds.), *Family social science* (pp. 25–31). St. Paul, MN: University of Minnesota.
- Olsson, M. B. & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 435-443.
- Ones, K., Yilmaz, E., Cetinkaya, B., & Calgar, N. (2002). Assessment of the quality of life of mothers of children with cerebral palsy (Primary Caregivers). *Neurorehabilitation and Neural Repair*, 19, 232-237.
- Osborne, L. A., & Reed, P. (2009). The relationship between parenting stress and behavior of children with autistic spectrum disorders. *Exceptional Children*, 76, 54-73.

- Pakenham, K. I. (2001). Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health and Medicine*, 6, 13-27.
- Parish, S. L., Rose, R. A., Grinstein-Weiss, M., Richman, E. L. & Andrews, M. E. (2008). Material hardship in U.S. families raising children with disabilities. *Exceptional Children*, 75, 71-92.
- Perlesz, A., Kinsella, G., & Crowe, S. (2000). Psychological distress and family satisfaction following traumatic brain injury: Injured individual and their primary, secondary, and tertiary carers. *Journal of Head Trauma Rehabilitation*, 15, 909-209.
- Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51, 109-124.
- Qualtrics Labs Inc. (2010). *Qualtrics survey software*. Provo, UT: Qualtrics Labs Inc.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D. Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115, 626-636.
- Resch, J.A., Mireles, G., Benz, M. R., Zhang, D., Peterson, R. L., & Grenweldge, C. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55, 139-150.
- Rivera, P. A., Elliott, T. R., Berry, J. W. & Grant, J. S. (2008). Problem-solving training for family caregivers of persons with traumatic brain injuries: A randomized clinical trial. *Archives of Physical Medicine and Rehabilitation*, 89, 931-941.

- Rivera, P. A., Elliott, T. R., Berry, J. W., Grant, J. S., & Oswald, K. (2007). Predictors of caregiver depression among community-residing families living with traumatic brain injury. *Neurorehabilitation, 22*, 3-8.
- Shearn, J. & Todd, S. (2000). Maternal employment and family responsibilities: The perspective of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 13*, 109-131.
- SPSS Inc. (2007). *SPSS 16.0 Brief Guide*. Chicago, IL: SPSS Inc.
- Stanton, A. L. & Snider, P. R. (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology, 12*, 16-23.
- Sue, V. M. & Ritter, L. A., (2007). *Conducting online surveys*. Thousand Oaks, CA: Sage.
- Talley, R.C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health, 97*, 224-228.
- Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities, 37*, 410-420.
- Taylor, S. E., Kemeny, M. E., Reed, G. M., Bower, J. E. & Gruenwald, T. L. (2000). Psychological resources, positive illusions, and health. *American Psychologist, 55*, 99-109.
- Tedeschi, R. G. & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*, 455-471.

- Underhill, A. T., LoBello, S. G., & Fine, P. R. (2004). Reliability and validity of the family satisfaction scale with survivors of traumatic brain injury. *Journal of Rehabilitation Research and Development, 41*, 603–610.
- Uphold, C. R. & Strickland, O. L. (1989). Issues related to the unit of analysis in family nursing research. *Western Journal of Nursing Research, 11*, 405-417.
- U.S. Department of Health and Human Services. (2000). *Healthy people 2010: Understanding and improving health* (2<sup>nd</sup> ed.). Washington DC: U.S. Government Printing Office.
- Veisson, M. (1999). Depression symptoms and emotional states in parents of disabled and non-disabled children. *Social Behavior and Personality, 27*, 87-98.
- Ware, J. E. (1993). *SF-36 health survey: Manual and interpretation guide* (1<sup>st</sup> ed.) Boston: Nimrod Press.
- Ware, J. E., Jr., Kosinski, M., Keller, S. D. (1996) A 12 item short form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*, 220-233.
- Warren, L., Wrigley, M., Yoels, W. C., & Fine, P. R. (1996). Factors associated with life satisfaction among a sample of persons with neurotrauma. *Journal of Rehabilitation Research and Development, 33*, 404-408.
- Webb, C. R., Wrigley, M., Yoels, W., & Fine, P. R. (1995). Explaining quality of life for persons with traumatic brain injuries 2 years after injury. *Archives of Physical Medicine and Rehabilitation, 76*, 1113-1119.

- Weston, R., Gore, P. A., Chan, F. & Catalano, D. (2008). An introduction to using structural equation modeling in rehabilitation psychology. *Rehabilitation Psychology, 53*, 340-356.
- Wilgosh, L., Nota, L., Scorgie, K. & Salvatore, S. (2004). Effective life management in parents of children with disabilities: A cross-national extension. *International Journal for the Advancement of Counselling, 26*, 301-312.
- Williams, J.W., Noël, P. H., Cordes, J. A., Ramirez, G., Pignone, M. (2002). Is this patient clinically depressed? *Journal of the American Medical Association, 287*, 1160-1170.
- Worcester, J. A., Nesman, T. M., Raffaele Mendez, L., M. & Keller, H. R. (2008). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74*, 509-525.
- Zhu, B., Walter, S. D., Rosenbaum, P. L., Russell, D. J., & Raina, P. (2006). Structural equation and log-linear modeling: A comparison of methods in the analysis of a study on caregivers health. *BMC Medical Research Methodology, 6*, 1-14.

## VITA

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