

Family Support: How Does Perceived Emotional and Instrumental Support for Latino Families  
with Children with Disabilities Relate to Caregiver and Family Well-Being?

By

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## Abstract

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Research shows that mothers who raise a child with a severe intellectual disability may experience more stress than mothers who care for typically developing children, or other caregivers who care for children with less severe intellectual disabilities (Olsson & Hwang, 2001, 2002; Stores, Stores, Fellows, & Buckley, 1998). These mothers may benefit from support. Latina mothers in particular who care for a child with an intellectual disability experience more stress and depression than non-Latina mothers (Blacher, Shapiro, Lopez, Diaz, & Fusco, 1997). The research examining the specific types and sources of support that are relevant to Latino families with children with disabilities is limited. In this study I examined the types and sources of support that are available to 146 mothers (84 Latina mothers, and 62 non-Latina mothers), with children with disabilities, and how that support relates to family and caregiver well-being. Specifically, I described the types and sources of familial support available to Latina and non-Latina mothers. Then, I examined the relation between perceived familial support and three dimensions of family and caregiver well-being: caregiver satisfaction with life, parenting self efficacy/empowerment, and family quality of life. Finally, I examined how culturally situated beliefs about family obligation moderate the relation between perceived support and family and caregiver well-being. Results indicate that Latina mothers had significantly less partner emotional support than non-Latina mothers. Latina and non-Latina mothers did not differ on other dimensions of support (i.e., instrumental). Also, partner emotional support and some instrumental support significantly predicted caregiver and family well-being. Finally, familism moderated the relationship between familial support and family well-being but not caregiver well-being. Implications for research and practice are discussed.

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## CHAPTER ONE

### Introduction

Mothers who care for children with serious intellectual disabilities face a challenging task. Research suggests that these mothers experience higher levels of negative psychological outcomes such as depression and stress than mothers who care for typically developing children or children with less serious disabilities (Olsson & Hwang, 2001, 2002; Stores, et al., 1998). These findings are based on small, unrepresentative samples. The stress of caring for a child with an intellectual disability can strain the emotional and financial resources of family caregivers, compromising their family quality of life, their parenting self-efficacy, and their ability to provide the best possible care to their child (Hodapp, 2002; Orsmund, Lin, & Seltzer, 2007).

Latina mothers in particular experience more stress and depression than non-Latina mothers who care for a child with a disability (Blacher, et al., 1997; Magaña, Seltzer, & Kraus, 2004). Latino families face structural risk factors that may impede their access to effective services including language barriers, poverty, discrimination, geographic mobility, and lack of familiarity with education and service delivery systems (Tienda & Mitchell, 2006). Even after controlling for these demographic characteristics, caring for a child with an intellectual disability continues to be particularly stressful for Latina mothers, above and beyond the effects of these demographic characteristics (Blacher, et al., 1997). These differences may be attributed to specific cultural notions of disability and family that may be prevalent in certain Latino communities.

In an effort to understand how mothers adapt to their role as a family caregiver, researchers have discovered that social support reduces the effects of stress on individuals and families caring for children with intellectual disabilities (Boyd, 2002; Dunst, Trivette, & Jodry, 1997; Horton & Wallander, 2001; Leung & Erich, 2002; Manuel, Naughton, Balkrishnan, Paterson, & Koman, 2003; Stoneman, 1997). For example, research shows that higher levels of support are correlated with less stress and depression, and positive family functioning (Stoneman, 1997). According to these studies, if a parent believes he or she has access to support, he or she will have an improved sense of psychological well-being and will face lower levels of negative psychological outcomes such as depression and stress. Social support is particularly important for Latina mothers' mental health (Aranda & Knight, 1997; Keefe, Padilla, & Carlos, 1979; Sabogal, Marín, Otero-Sabogal, Marín, & Perez-Stable, 1987). Family support, in particular, has been shown to reduce the effects of stress and prevent mental illness for Latina mothers who care for a child with a disability (Keefe, et al., 1979).

Despite the extensive research within this field focusing on how support is correlated with lower levels of depression and stress among White, middle-class parents who care for children with disabilities, little research exists that examines the relation between support and parent well-being for culturally and economically diverse families, specifically Latino caregivers who care for children with intellectual disabilities (Bailey, et al., 1999). We also know very little about the ways that family members draw upon the support available within the family. Current

research has been less detailed in understanding the specific types and sources of support that are useful to mothers who care for children with disabilities and how that support relates to family and caregiver outcomes; particularly for Latina mothers who care for children with disabilities. Given that the welfare of children with intellectual disabilities depends on the ability of the caregiver to not only nurture and love her child, but also to advocate for and obtain services critical to the child's healthy development, it is essential that researchers identify the ways in which caregivers use family and social resources to confront the challenges involved in caring for a child with an intellectual disability.

The current study is designed to address this gap in the research by exploring the familial support available to Latino families who care for children with intellectual disabilities. This project has three aims: (1) to identify the types and sources of support that are available to Latina and non-Latina mothers; (2) to examine the relation between familial support and family well-being within a culturally diverse sample; and (3) to understand whether culturally situated beliefs about family obligation moderate the relationship between a mother's perceived support and her family and personal well-being.

I frame my research within the stress and coping perspective. Stress is a specific transactional relationship that an individual has with his or her environment that is constantly changing as his or her appraisals of the stressful event change (Folkman, 1984). Individuals' appraise certain events as stressful or not stressful based on their resources and personal characteristics. Most of the empirical research in this area identifies support as alleviating the stress or caregiving burden of the caregiver in order to enhance his or her outcomes. In my study, I will build upon the stress and coping perspective as adapted by McCubbin & Patterson (1983) to understand the role of social support in promoting the well-being of Latina mothers who care for a child with an intellectual disability.

### **Theoretical Frame**

In the following section, I will explore the theoretical underpinnings of social support for families with children with disabilities and examine how the stress and coping perspective is a useful frame in which to examine the types and sources of these supports.

#### **Social Support: Definitions and Models**

Early researchers defined social support as an individual's perceptions that he or she is a valuable member of a social network (Cobb, 1976). More recent researchers working in this field defined social support as more multidimensional. Cohen and Wills defined social support as a construct consisting of instrumental support, informational support, esteem or emotional support, and social companionship (Cohen & Wills, 1985). Similarly, Dunst and colleagues (1986) defined social support as physical and instrumental assistance, emotional support, and information and resource support (Dunst, Trivette, & Cross, 1986).

Although broad and multidimensional definitions of social support were developed throughout the 1980s, researchers were still working to understand how to most effectively and appropriately measure social support, and what effects it had on certain outcomes. This uncertainty led researchers to further develop the concept of social support. Barrera (1986) and others believed that social support was insufficiently specific to be measured effectively and they developed three broad indicators of social support used to organize and operationalize (i.e., measure) the concept. *Social embeddedness* refers to the connections that individuals have to significant others in their social environments (Barrera, 1986; Sarason, 1974). Measures of social embeddedness use broad indicators to determine the presence of social ties (e.g., marital status, participation in community support groups). Although this concept is not a direct measure of social support, as it does not measure how supportive these individuals are, it indicates the presence of individuals that could be potential sources of support for the family. *Perceived social support* refers to how individuals personally interpret a reliable connection to others (Barrera, 1986). Measures of perceived social support incorporate the perceived availability (e.g., access to) and adequacy (e.g., quality of) of supportive ties (Barrera, 1986). These measures attempt to capture the individuals' beliefs that adequate support would be available if needed. *Enacted support* refers to the actions that others perform to provide assistance to another person (Barrera, 1986). Measures of enacted support assess what conduct individuals actually engage in when they provide support.

Furthermore, the importance of the perception of social support has illustrated highly consistent research findings, particularly in its relation to health outcomes (Antonucci & Israel, 1986; Blazer, 1982; Sarason, Sarason, & Pierce, 1990). Current research illustrates that perceived support, rather than enacted support, mediates the relationship between a child's disability and a caregiver's psychological well-being (Lunsky & Benson, 2001; Taylor & Lynch, 2004). The perception of a strong support network affects individuals more than enacted support. Measures of perceived support allow researchers to understand whether the recipient feels supported by a person or an action. The assumption is that if someone perceives support they may in fact desire the support. In contrast, measures of enacted support are less useful because researchers may not know whether the recipient actually desires the support. In addition, it may be difficult to measure enacted support because it would involve consistent observation. Few studies measure enacted support among individuals.

In fact, Cohen and Wills (1985), in their analysis of the process by which support relates to well-being, identify perceived support as a useful type of support that relates to well-being. They developed two models to address the effects of social support on certain outcomes: the buffering model and the main effects model. The main difference between these two models involves how social support is measured. Researchers adhering to the buffering model use measures that assess the perceived availability of interpersonal resources that protect ('buffer') individuals from the ill effects of stress. Thus, the buffering model addresses the differences in the adjustment of individuals based on the amount of support, in stressed, rather than unstressed circumstances. In contrast, researchers adhering to the main effects model use measures of support that assess an individual's degree of integration into a larger social network. In this

model, it is assumed that social support has a beneficial effect on individuals regardless of whether the individual is under stress (Cohen & Wills, 1985). Both of these models are viable options for assessing how social support relates to well-being.

The buffering model is more appropriate for my study because the support measures I used more specifically examine the perceived availability of familial support available to mothers who care for children with disabilities, which is commonly thought to produce stressful circumstances. In the following section I will briefly describe the components of the stress and coping perspective and how it is useful for understanding the relation between familial support and caregiver well-being, and between familial support and family well-being for Latina mothers caring for children with disabilities.

### **The Stress and Coping Perspective**

One of the main theoretical perspectives that aligns with the buffering model is the stress and coping perspective. Building on previous research, most of the work examining families with children with disabilities operates within a stress and coping perspective; social support contributes to families' health and well-being by protecting caregivers from the adverse effects of stress.

The stress and coping perspective is focused on examining the psychological stress of an individual. Psychological stress is a relationship between the person and the environment that is appraised by the person as challenging or exceeding his or her resources and endangering his or her well-being. The judgement that a particular person-environment relationship is stressful hinges on the individual's cognitive appraisal of the event; the meaning of the event to the individual (Folkman, 1984). This relational definition is different from other approaches that view stress as a stimulus (i.e., a stressor) that is isolated from environmental influences and that focuses on the individual's subjective interpretation of how it will affect his or her needs or beliefs. Within the stress and coping perspective, stress is not owned by the individual or the environment, nor is it a stimulus or a response (in a behaviorist sense). Rather, stress is a specific transactional relationship between the individual and his or her environment that is constantly changing as the individual's appraisals of the stressful event shift (Folkman, 1984).

The stress and coping perspective includes a cognitive appraisal of the stressful event and an understanding of the supportive actions that mitigate the stressful event. In the cognitive appraisal of the event, the individual identifies an event as stressful, and identifies the type of support that may be useful in coping with the stressful event. There are two types of cognitive appraisals: (1) primary appraisals: the individual evaluates the significance of a specific event and how it relates to his or her well-being; and (2) secondary appraisals: the individual identifies and evaluates certain resources that he or she may have to cope with the stressful event. Primary appraisals include an individual's judgment as to whether a particular event is either stressful (e.g., harmful, threatening, or challenging) or benign. Stressful appraisals may include an unexpected death of a loved one, or learning of a child's disability. A primary appraisal is shaped

by an array of individual-level (e.g., beliefs or preexisting perceptions about reality) and environmental-level factors (e.g., the resources available to cope with the stress) (Lazarus & Folkman, 1984, Folkman, 1984).

In a secondary appraisal, individuals evaluate the resources they have to cope with a stressful event. These resources may include physical, social, psychological, and material support that are evaluated in accordance with the demands of the situation. Physical resources represent the individual's health and energy level; social resources represent the individual's social network and support systems (e.g., emotional and instrumental support). Psychological resources represent beliefs that an individual can draw upon to solve a problem, maintain hope, and build self-esteem. Material resources refer to tangible items (e.g., money, equipment) that the individual can use to cope with a stressful event (Folkman, 1984).

After the individual appraises the stressful event, the individual elicits supportive actions to ameliorate the stressful event. In this stage, the individual assumes that the supportive actions will be effective in promoting coping and in reducing the effects of the stressor (e.g., the burden of caring for a child with a disability). However only when the type and amount of support match the demands of a stressor will the supportive actions ameliorate the stressor (Lakey & Cohen, 2000). For example, financial support may be useful if an individual lost a job, but useless for a caregiver who wants to expand her 5-year old child's level of independence when dressing him or herself.

### **Stress and Coping for Families and Children with Disabilities**

In the field of families and children with disabilities, the stress and coping perspective is considered the most widely used theoretical perspective to examine social support because it assumes that such support reduces the effects of stressful life events on an individual's health and well-being. Up until now, the previous empirical research in this field has assumed that caregivers feel more stress and carry a greater caregiving burden because they have a child with a disability. Therefore, most of the work in this area has explored families' levels of support through this lens; the increased stress and caregiving burden from having a child with a disability requires social support to mitigate the stress and enhance caregivers' ability to cope with having a child with a disability (Barrera, 1986; Cobb, 1976; Cohen & Wills, 1985; Lazarus & Folkman, 1984, McCubbin & Patterson, 1983, Patterson, 1993).

Along with the stress and coping perspective as exemplified by Lazarus and Folkman (1984), Reuben Hill's ABCX model was one of the earliest conceptual models used to describe how stressful events interact with a family's resources. The stressor event (A), interacts with the resources that the family has to alleviate the stressor (B), which interacts with the family's definition of the stressful event (C), to produce the crisis (X). A family's positive or negative adaptation to the stressful event is determined by the interaction of the stressor, with the family's resources to alleviate the stressor, and the family's definitions of the stressful event. The focus of this model was to examine the unique characteristics of the family that preceded the crisis;

specifically the protective factors that allow the family to cope with the stressful event (Hill, 1958).

McCubbin and Patterson (1983), built upon Lazarus and Folkman's cognitive theory of stress and coping, and Hill's ABCX crisis model, with the Double ABCX and the Family Adjustment and Adaptation Response model (FAAR). The Double ABCX model expands upon Hill's model by redefining the "pre-crisis" variables; the multiple demands or conditions that are present in the family when the stressful event occurs, and adding "post-crisis" variables; the adaptive resources that are developed and strengthened as a result of the demands of the stressor. For example, Hill (1958), describes the family's demands as one stressor leading to one stressful event that remains static over time (Hill, 1958). McCubbin and colleagues (1983), on the other hand, view the family's demands as a "pile up" of several stressors that shape the way the family adapts to its current situation. Families modify and adapt the meaning of the stressful event as their resources and perceptions of the event change. In some cases families no longer view the event as stressful, but as a positive adaptation. Furthermore, borrowing from Lazarus and Folkman's theoretical notions of the stress and coping perspective as an appraisal of the relationship between the person and the environment, McCubbin and Patterson describe the Double ABCX model as a way in which families perceive the stressful event and, over time, how they adjust and adapt to the stressful event based on the resources available to them and on the families' appraisal of the stressful event (McCubbin & Patterson, 1983).

In order to more effectively understand the type of adjustment and adaptation that occurs over time, McCubbin and Patterson developed the FAAR model. The goal of this model was to understand how families achieve balance between the demands of their environment (the stressors), and the family's capability for handling those demands. The FAAR model consists of three phases. The first phase, the adjustment phase, involves a family's initial and short-term response to a stressful event. During the adjustment phase, family members may avoid or accept the stressor. In the second phase, the adaptation phase, families restructure their routines and daily activities to adapt to the stressful event over a longer period of time. In this phase, family members are aware of the stressful event, they develop a shared definition of the stressful event, which leads them to implement structural changes in their lives to adapt to the stressful event. Finally, once the family members have successfully adapted to the stressful event, they enter into a consolidation phase where they accommodate their newly restructured family unit in an attempt to maintain balance and achieve a new sense of family unity (McCubbin & Patterson, 1983, Patterson, 1993).

McCubbin and Patterson's Double ABCX and FAAR models have more recently been used in the field of families with children with disabilities to illustrate the positive adaptations and adjustments that families make when they have a child with a disability (Hastings & Taunt, 2002; Blacher & Baker, 2002). The stress and coping perspective as illustrated by McCubbin and Patterson's Double ABCX and FAAR models frame my study in two distinct ways. First, I examine how Latina and non-Latina mothers appraise (i.e., perceive) the resources available to them to satisfy their caregiving duties. Second, I examine the type of adaptation that may occur

by identifying how mothers' perceived resources (i.e., familial supports) relate to their overall well-being (i.e., family quality of life, individual satisfaction with life, and parenting self-efficacy).

Overall, this study will examine the utility of the stress and coping perspective as put forth by McCubbin & Patterson (1983), in understanding the role of social support in promoting the well-being of mothers in an ethnically diverse sample. While the current theoretical perspective was originally developed based on a sample of families who had a loved one (e.g., father/husband) held captive in the Vietnam War, the more recent samples have examined how primarily White, middle class families adjust and adapt to caring for children with disabilities. In this study I test the relevance of the stress and coping theory with respect to a new population. I examine the appraisals of support among Latina mothers and non-Latina mothers who care for a child with a disability, in an attempt to understand their perceptions of the resources that they have available to them. Specifically, I will explore whether there is variation among Latina and non-Latina mothers in their appraisal of potential stressors (e.g., caring for a child with an intellectual disability), and whether there are differences between Latina and non-Latina mothers in the effect on stress-mediating variables such as support.

## **Literature Review**

In order to understand the relation between perceived support and well-being for families with children with disabilities, I will first define the types and sources of support that are identified in the literature on families who care for a child with a disability. Next, I will examine the relation between support and well-being for families with typically developing children, families who care for a child with a disability, Latino families with typically developing children, and Latino families who care for a child with a disability, with particular attention on family and caregiver well-being as exemplified by family quality of life, caregiver life satisfaction, and parenting self-efficacy. The goals of this review are to understand: (1) the specific supports that are available to each group of families; and (2) whether certain types of supports are more useful for a particular group. I will also examine the relevant culturally-situated beliefs about family obligation within Latino families.

### **Informal and Formal Perceived Support**

Previous research examining social support illustrates that the most effective type of support involves the individual's closest relationships (Sarason, et al., 1990). The literature on children and families with disabilities identifies two types of social support: informal and formal support. Informal support generally consists of supporters within the family unit, including extended family, or close friends (Boyd, 2002). Informal supporters are most likely to provide emotional support, social companionship, and care taking assistance (Glidden & Schoolcraft, 2007). The current research that examines the relation between informal support and well-being indicates that perceptions of informal support are associated with lower parental stress, greater parent empowerment, and higher levels of marital satisfaction (Canary, 2008). For example,



Hassal and colleagues identify family support, particularly marital support, as positively related to maternal well-being. However, as with the other studies examining the relation between informal support and well-being, there is limited discussion as to the type of support (e.g., emotional support, care taking assistance, etc.) that constitutes informal support (Hassal, Rose, McDonald, 2005).

Formal support is provided by professionals such as doctors, teachers, psychologists, occupational therapists, and speech therapists who may provide medical, informational, advocacy, and other types of support (Glidden & Schoolcraft, 2007). According to Boyd (2002), formal supports are social, psychological, physical, or economic support that is provided for free or in exchange for a fee by an organization (Boyd, 2002). The studies that identify the relation between formal support and well-being are inconsistent. Some studies found that formal support is related to lower stress, greater well-being, and empowerment among parents (Dempsey, Foreman, Sharma, Khanna, & Arora, 2001; Honig & Winger, 1997), whereas other studies show that formal support is not meeting the needs of these families (Maes, Broekman, Dosen, & Nauts, 2003; Wang, Mannan, Poston, Turnbull, & Summers, 2004).

These definitions of informal and formal support primarily identify whether the source of the support is useful for families, rather than identify the specific supportive activities that are useful for families (Boyd, 2002). As research shows that families express a preference for informal as compared to formal support (Boyd, 2002; Canary, 2008), it may be useful to focus on how specific types of informal support relate to family and caregiver well-being.

### **Support for Parents Who Care for Typically Developing Children**

Parenting is a challenging task. Parents' behaviors will shape their children's academic and social development throughout their childhood. Research shows that parents who are more efficacious in their roles as parent raise children who are more socially adept (Brody, Flor, Gibson, 1999; Jones & Prinz, 2005; Teti & Gelfand, 1991). Research also shows that parent well-being is enhanced with support from family members and friends (Belsky, 1981; Colletta, 1983). In the following discussion I will identify the types of support that are useful for parents who care for a typically developing child and how these supports relate to parent and/or family well-being. The goal of this section is to understand what support looks like for parents who care for typically developing children, and in subsequent sections, compare how these supports compare to the types and sources of support that are available to parents who care for a child with a disability. For parents who care for a typically developing child, different supports may be considered useful than for parents who care for a child with a disability.

The literature on parents who care for a typically developing child identifies informal support as useful to parents. Spousal emotional support, in particular, serves as a key resource, with the potential of exerting the most positive or negative effects on parenting (Belsky, 1981; 1984; Colletta, 1983; Crnic, Greenberg, Ragozin, Robinson, Basham, 1983). For example, a mother's affirmation of her respect, pride, and support for her husband was related to whether

her husband praised their preschool child (Sears, Maccoby, & Levin, 1957). In another study by Bandura and Walters, (1957), mothers who tended to nag or punish their preschool children received less affection and warmth from their husbands (Bandura & Walters, 1957). Also, Crnic and colleagues (1983) studied 105 mothers and their four-month old infants and found that partner emotional support had the most positive effect on the mother's well-being (i.e., mother's mental health) (Crnic, et al., 1983). Thus, the marital relationship indirectly influences parenting by impacting the parent's general psychological wellbeing, thus affecting their parenting skills (Belsky, 1984).

Other sources of informal support are also important for families who care for a typically developing child (Crnic, et al., 1983; Cutrona & Troutman, 1986; Hetherington, Cox, & Cox, 1977; Powell, 1979). For example, Powell found that mothers of preschoolers were more verbal and emotionally responsive to their children when they had more frequent contact with their own friends (Powell, 1979). While it is certainly possible that these mothers may be more sensitive and socially engaged, thus allowing them to more readily develop informal social supports and to be more emotionally responsive to their children, it is the presence of informal supports that is important for families who care for typically developing children. Also, Pascoe and colleagues (1981), found that mothers who had consistent contact and support from their social networks, avoided punishment and restriction of their preschool children (Pascoe, Loda, Jeffries, & Easp, 1981). Furthermore, Colletta (1979), interviewed three groups of mothers that varied in income level and marital status and found that informal support was negatively associated with parent punitiveness and restrictiveness. Colletta concluded that those parents with a minimal amount of informal support exhibited more authoritarian punishment techniques (Colletta, 1979). Thus, the benefits that parents receive from informal support is related to the parents' psychological wellbeing by specifically contributing to the parents' sense of self-esteem, which results in greater patience and sensitivity in their role as parent (Belsky, 1984; Cochran & Brassard, 1979).

The limited studies examining formal support for parents with typically developing children show that parents also utilize formal support to enhance their parenting skills (Stevens, 1988; Telleen, Herzog, & Kilbrane, 1986). For example, Stevens (1986), examined three groups of mothers: Black adult mothers, Black teen mothers, and White adult mothers to understand how informal and formal sources of functional support (i.e., instrumental) related to their parenting skills. He found that for both the Black adult mothers and the Black teen mothers, they relied more heavily on informal sources of support (i.e., family and friends) and the White adult mothers relied on informal and formal sources (e.g., a childrearing professional) of support (Stevens, 1988). Telleen and colleagues also examined whether a formal family support program consisting of parent support groups and parent education classes was associated with a parent's well-being (i.e., lower parenting stress). They found that parents' participation in the parent support group contributed to parents feeling less socially isolated and more efficacious in their role as a parent (Telleen, et al., 1986). Although formal support may be considered useful for these families, parents found most effective those formal supports that most closely resemble informal support. For example, Telleen and colleagues found that parents who engaged in parent support groups experienced less stress and less social isolation, but there was no effect on parent

well-being for parents who participated in parent education classes. Informal support remains the preferred method of support for parents who care for typically developing children (Edwards, & Gillies, 2004).

In sum, for parents who care for typically developing children, spousal support is critical in that it significantly relates to parent well-being (i.e., parent self-efficacy). Spousal support includes the spouse's provision of emotional support to the caregiver through words of praise and encouragement in his/her role as a parent. Other types of informal support (e.g., from family and friends) are also important and significantly relate to caregiver well-being (i.e., parenting self-efficacy). Further, limited research acknowledges the utility of formal support for these families, but this research shows that the formal supports that most closely resemble informal supports (e.g., community support groups) are significantly related to caregiver well-being.

The current literature regarding the relation between support and well-being for families that care for typically developing children is limited in two ways. First, the research does not adequately define specific types (e.g., emotional, instrumental, material) of formal or informal support. Understanding the specific supports that relate to caregiver well-being is important for practitioners and informal supporters in that it will allow them to capitalize upon the most useful supports to enhance caregiver well-being. Second, the current literature does not examine the relation between support and other family-level outcomes (e.g., family quality of life). Examining the relation between support and more general family well-being is useful to enhance the well-being of every family member. Future research should address these limitations.

### **Support for Parents Who Care for Children with Disabilities**

Parenting a child with a disability can be an even more challenging task than parenting a typically developing child. In fact, research indicates that mothers who care for a child with a serious disability experience higher levels of negative psychological outcomes (e.g., stress) than mothers who care for a child with a less serious disability or a typically developing child (Olsson & Hwang, 2001, 2002; Stores, et al., 1998). The stress of caring for a child with a disability provokes feelings of loss, helplessness, and failure for the mother, thereby increasing her risk for stress and depression (Olsson & Hwang, 2001). However, research also shows that if these parents have adequate support, they have less stress and depression, and an improved sense of well-being (Boyd, 2002; Horton & Wallander, 2001; Leung and Erich, 2002, Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; Stoneman, 1997). In the following discussion I will identify the types of support that are useful for parents who care for a child with a disability and how those supports relate to caregiver and family well-being. The goal of this part of the literature review is to understand how certain types and sources of support for parents who care for a child with a disability compare with the types and sources of support that are useful for parents who care for a typically developing child. As parents with a child with a disability experience greater emotional distress due to a variety of factors including the child's disability, one may assume that these parents should receive more varied and targeted types and sources of support to address their needs, than parents who care for a typically developing child.

Informal support may be considered useful for parents who care for a child with a disability as informal support primarily consists of emotional support, and addresses the emotional insecurities that some mothers identify with having a child with a disability (e.g., diminished self-efficacy in childrearing, an inability to pursue one's personal goals) (Boyd, 2002; Olsson & Hwang, 2001). In fact, current research identifies informal support as a useful source of support for these families (Boyd, 2002; Canary, 2008). For example, Herman & Thompson (1995) identified informal support (support from spouse, family, and friends) as useful to parents, particularly when more formal types of social support (e.g., support groups, church groups) were unavailable (Herman & Thompson, 1995). In another study by Bristol, (1984), she found that the most important type of support for mothers who cared for a child with autism was spousal support, the mother's relatives, and other parents who cared for a child with autism (Bristol, 1984).

Formal support may be considered equally useful for families who care for a child with a disability as this type of support includes service providers (e.g., speech therapists, and teachers) who have experience and knowledge working with children with disabilities. Families may rely on the knowledge of these formal supports to better understand their child, particularly if their child has a difficult temperament, or exhibits problem behaviors that may be related to the child's disability. In fact, research indicates that parents experience a lower sense of well-being, and a diminished ability to effectively care for their child due in part to the child's difficult behaviors that may be related to his/her disability (Beckman, 1983, Floyd & Gallagher, 1997; Holroyd & McArthur, 1976). The literature examining how parents who care for a child with a disability perceive formal support was found to be somewhat useful (Peck, 1998; Bristol, 1984; Krauss, Upshur, Shonkoff, & Hauser-Cram, 1993). For example, Krauss and colleagues (1993) examined the effects of organized support groups for parents who care for children with a variety of disabilities (e.g., Down syndrome, motor impairment, developmental delay), and found that mothers who consistently attended the support groups reported higher levels of perceived support. However, results also showed that mothers who consistently attended these support groups reported elevated levels of personal strain on their role as caregiver and on the well-being of the family (Krauss, et al., 1993). Thus, although one may expect formal support to be useful, the research is inconsistent as to its effectiveness.

Current research indicates that support mitigates stress and enhances well-being (Boyd, 2002; Horton & Wallander, 2001; Leung and Erich, 2002; Manuel, et al., 2003). Understanding how support relates to well-being for families who care for a child with a disability is important so that practitioners can develop targeted family centered services to produce effective results. The research examining the relation between support and well-being for caregivers who rear a child with a disability clearly establishes a relation between support and well-being, but fails to identify the most effective types of support that enhance well-being. Stoneman (1997), in her review of the literature, found that high levels of support are correlated with less stress, less depression, positive family functioning, greater parental self-efficacy, reduced caregiving burden, and greater satisfaction with life (Stoneman, 1997).

More recent studies show similar results, including that increased levels of informal and formal support are associated with better family functioning like improved emotional health, and lower maternal distress (Boyd, 2002; Horton & Wallander, 2001; Leung and Erich, 2002; Manuel, et al., 2003). For example, Leung and Erich (2002) examined primarily White, middle-class parents and their adoptive children with cerebral palsy, learning disabilities, and psychological disorders. They found that greater supports from informal and formal sources were associated with better family functioning (e.g., better emotional health) (Leung and Erich, 2002). Also, Horton and Wallander (2001) examined primarily White, middle-class mothers who cared for children with spina bifida, cerebral palsy, or diabetes. They found that mothers who received social support experienced lower maternal distress (Horton and Wallander, 2001). Finally, Manuel and colleagues (2003) examined primarily White mothers who cared for a child with cerebral palsy. They found that mothers who reported low levels of perceived social support had more depressive symptoms than mothers who perceived high levels of social support (Manuel, et al., 2003). The above studies clearly illustrate that if a parent believes he or she has access to support, he or she will have an improved sense of psychological well-being. However, they neglect to clearly define the types of support that enhance well-being.

In sum, consistent with the literature on support for parents who care for typically developing children, informal support appears to be useful in mitigating stress and enhancing caregiver well-being for parents who care for children with disabilities. There is less consistent evidence identifying the effectiveness of formal support, and its relationship to caregiver well-being. The current literature is limited in three ways. First, as with the literature examining support for parents who care for typically developing children, the research does not adequately define specific types (e.g., emotional, instrumental, material) and sources (e.g., specific supporters) of support. As parents who care for a child with a disability experience greater stress and depression in caring for their child than parents who care for a typically developing child, and support has been shown to mitigate that stress and enhance well-being, it is particularly important to identify the specific types and sources of support that are useful for these parents in order to develop targeted interventions that enhance caregiver well-being.

Second, as with the literature examining the relation between support and well-being for parents who care for typically developing children, there is some research examining the relation between support and caregiver well-being, particularly parenting self-efficacy, but there is limited research that examines the relation between support and other family-level outcomes (e.g., family quality of life). For example, recent research in this area indicates that siblings of children with disabilities are more negatively impacted (e.g., have worse developmental outcomes) over time than siblings of typically developing children (Neece, Blacher, & Baker, 2010). Furthermore, the few studies that examine the relation between support and sibling well-being identify positive adaptations for the typically developing sibling (Rivers & Stoneman, 2003). Thus, it is important to examine how support relates to more specific family-level outcomes that may benefit not only parents, but also the rest of the family.

Finally, although the research examining the relation between support and well-being for families with children with disabilities is extensive, little research exists that examines the relation between support and well-being for culturally and economically diverse families, specifically Latino caregivers who care for a child with a cognitive disability (Bailey, et al., 1999). In an effort to address these gaps in the literature, in the current study, I identify and define certain types and sources of support that may be useful to Latina and non-Latina mothers who care for a child with disabilities. I also examine the relation between these supports and well-being for Latina mothers as compared to non-Latina mothers with respect to three aspects of family functioning: family quality of life, individual life satisfaction, and parenting self-efficacy.

### **Family Quality of Life**

The family quality of life construct was born from decades of research examining individual quality of life (Zuna, Turnbull, & Summers, 2009). This movement abandoned earlier notions of separating and institutionalizing individuals with disabilities and promoted the values of equity, self-determination, and inclusion of individuals with disabilities. Family quality of life adheres to similar values and is recognized as an important concept in the practice of family centered services<sup>1</sup>. Zuna and colleagues (2010) define family quality of life as “...a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family level needs interact” (Zuna, Summers, Turnbull, Hu, & Xu, 2010, p. 262). Family quality of life, in contrast with individual quality of life, considers the well-being of all family members specifically in terms of what it takes for each family member to have a good life together with his or her family (Poston, et al., 2003). The goal of this construct is to enhance the capacity of families to meet the special needs of their child (Bailey, et al., 1998). The main factors that promote family quality of life are based on a families’ ability to: (1) overcome their challenges; (2) be satisfied with their accomplishments; and (3) feel empowered and agentive to live the lives they wish to live (Brown & Brown, 2004). If families rate their satisfaction in these three areas as high, they are considered to have a high family quality of life.

As the family quality of life construct is still in its conceptualization process, most of the empirical work examining family quality of life for families with children with disabilities focuses on developing a valid and reliable measure to assess this concept (Hoffman, et. al., 2006; Summers, et. al., 2005). Little research exists that examines the relations between certain predictors such as support and family quality of life (Schalock, 2004, & Summers, et. al., 2007). One study by Summers and colleagues (2007), examined the relation between service provider support (or family’s satisfaction with services) and family quality of life on a sample of 240 primarily White, high school educated, middle-class families with children with disabilities. Findings showed that families rated their general family quality of life as high, with the lowest

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<sup>1</sup> Family centered services are designed for children and families in early intervention. Based on the resources of each family, the goal is for families to partner with service providers and gain the necessary skills to empower them to effectively meet the needs of each family member (Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker, & Wagner, 1998).

ratings on the emotional well-being sub-scale, and the highest ratings on physical/material well-being and disability-related support sub-scale. In general, 64% of the sample rated their family quality of life as between moderate and high. With respect to examining the relation between support and family quality of life, there was a significant relationship between a participant's perceived adequacy of the services that he or she received and his or her perceptions of his or her quality of life (Summers, et. al., 2007).

In another qualitative study that relied upon focus groups and interviews, Poston and Turnbull (2004), examined the relation between religious or spiritual support and family quality of life on a sample of White or African Americans individuals who cared for individuals with disabilities. They found that the strength that participants gained from their spiritual well-being and engagement in religious practices was related to participants' overall family quality of life (Poston & Turnbull, 2004). Although the conceptualization of family quality of life is still in its infancy, the few studies that examine the relation between support (e.g., service provider, and religious support) and well-being illustrate that when there is adequate support, family quality of life is enhanced for families with children with disabilities.

### **Individual Life Satisfaction**

Although family quality of life may be an optimal way to measure family-level outcomes, research continues to focus on mothers' perceptions of and satisfaction with support for several reasons. First, current research illustrates that mothers are the primary caregivers of children with disabilities (Glidden & Schoolcraft, 2007). Second, studies show that mothers who care for children with intellectual disabilities have significantly higher negative outcomes such as depression and stress than mothers who care for typically developing children (Olsson & Hwang, 2001, 2002; Minnes, 1998). Third, these studies show that fathers reported lower levels of depression than mothers (Olsson & Hwang, 2001, 2002). Fourth, in these studies, where differences are found between mothers and fathers, mothers generally express a greater need than fathers for family and social support (Bailey, Blasco, & Simeonsoon, 1992). Therefore, understanding mothers' perceptions of and satisfaction with the types and sources of support that are useful and relevant to them, is necessary to promote healthy child and family outcomes.

In an effort to understand mothers' perceptions of and satisfaction with support, I chose to examine the mother's individual psychological well-being. To that end, the current study assesses a mother's individual quality of life, or life satisfaction, and a mother's sense of empowerment or self-efficacy in childrearing. Individual life satisfaction is defined as a global assessment of an individual's quality of life as per his/her chosen criteria (Diener, Emmons, Larson, Griffin, 1985). This concept examines more general statements of an individual's life satisfaction; the individual judges his or her sense of life satisfaction as compared to a certain "appropriate" standard that the individual sets for himself or herself, rather than an externally imposed standard (Diener, et. al., 1985). The Satisfaction with Life Scale is a five-item scale that asks global questions about an individual's life satisfaction. Although it is not as readily used in research examining families who rear a child with a disability, the Satisfaction with Life concept, and the

measure developed by Diener and colleagues (1985), is a widely used measure in the general population.

There are a limited number of studies that examine the relation between support and life satisfaction for families with children with disabilities. One study by Sloper and colleagues (1991) studied a sample of 181 White mothers and fathers with children with Down syndrome. The authors measured whether material, social, psychological, or physical resources related to a family's life satisfaction. They found that the amount of social support reported by the mother was positively related to her individual life satisfaction (Sloper, Knussen, Turner, & Cunningham, 1991). In another study by Crnic and colleagues (1983), 105 mothers of premature and full-term infants were assessed to determine how social support affects their individual life satisfaction. Results showed that mothers' perceived support was related to their life satisfaction. Specifically, family and community support significantly predicted individual life satisfaction, whereas support from friends did not predict individual life satisfaction (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983).

### **Parenting Empowerment/Self-efficacy**

In addition to understanding individual and family quality of life, I have also chosen to examine the mother's sense of parenting self-efficacy in caring for her child with a disability. Building on social learning theory, self-efficacy relates to an individual's judgments about how well he or she can act in a given situation (Bandura, 1982). Parenting self-efficacy has emerged as a powerful predictor of specific parenting practices and as a mediator of certain parent (e.g., maternal depression) and child outcomes (e.g., child temperament) (Coleman & Karraker, 1998).

Empowerment has also been considered an important construct for measuring a family's strengths and capabilities. The definition of empowerment has been debated over recent years. In the field of families and children with disabilities, Dunst and colleagues define empowerment as the enhancement of families' capabilities as a way of improving their capacity to negotiate service systems (Dunst, Trivette, & Deal, 1988).

Both empowerment and self-efficacy have long been considered important constructs for families with children with disabilities. For example, Dunst and colleagues have made valuable strides in developing a model of individual and family empowerment focused on examining the strengths and capabilities of individuals and families, and the capacity to use these strengths to access the resources necessary to meet their needs. According to Dunst and colleagues, empowerment considers the "help-seeker," or the individual requiring support, as the agentive individual identifying his or her needs, understanding the options available to meet those needs, and engaging in the specific behaviors to meet those needs. Whereas the "help-giver" or the supporter, is responsible for supporting, encouraging, and providing the opportunities for the help-seeker to acquire the competencies necessary to access the appropriate supports and resources (Dunst, et al., 1988). The goal of empowerment is therefore to enable individuals and families with children with disabilities to become more competent and capable in accessing the



services and supports necessary for their child and family. In the following review, I will identify literature that examines the relation between support and empowerment and support and parenting self-efficacy for families with children with disabilities.

With the exception of Dunst and colleagues (1988, 1994), who have examined one aspect of empowerment (e.g., strengths) for individuals and families with children with intellectual disabilities, there is limited work that both succinctly defines and thoroughly examines empowerment. Koren and colleagues (1992) define empowerment as a set of personal “states,” that may change over time or in response to certain life experiences (Koren, DeChillo, & Friesen, 1992). In other words, empowerment refers to the continuous perceived ability of individuals to act on their own behalf to maintain and achieve control over their own lives (Koren, et al., 1992). The goal of this measure is to get an accurate and complete understanding of an individual’s sense of empowerment in his or her role in caring for his or her child with a disability.

Trivette and colleagues (1996), examined the relation between empowerment and well-being in two studies with two different samples (i.e., Study 1: 128 participants, Study 2: 81 participants), mostly mothers (98%). Both samples had children in a family centered early intervention program that primarily worked with children with developmental disabilities or who were at risk for poor developmental outcomes due to biological (e.g., low birthweight) or environmental (e.g., poverty) factors. Mothers who worked with social workers and nurses perceived a greater sense of empowerment than mothers who worked with early educators or speech and language therapists because the nurses and social workers engaged in participatory support (e.g., service providers who sought to capitalize on and mobilize the desired resources of the family), rather than relational support (e.g., empathy, reflective listening, etc.) (Trivette, Dunst, & Hamby, 1996). The fact that participatory support was significantly related to mothers’ empowerment as compared to relational support for these families, suggests that service providers must go beyond their traditional training required to support a family, to understand and utilize the unique supports that are important to each family. In my study, I examine six different types and sources of familial support that may be useful to Latina and non-Latina mothers who care for a child with a disability, thus acknowledging that support may look different for different families.

Within the field of families and children with disabilities, parent self-efficacy has been explored both as a predictor of parent outcomes and as a parenting outcome. The limited research examining parent self-efficacy as a predictor of parent outcomes finds that parent self-efficacy predicts parental stress (Frey, Greenberg, & Fewell, 1989; Krauss, et al., 1993). In other words, the lower the parent’s self-efficacy, the higher the parent’s level of stress. There is also limited research examining the relation between support (as the predictor) and parent self-efficacy (as the outcome). The few studies that examine self-efficacy as an outcome identify more specific variables (e.g., child’s behavioral characteristics) as predictive of parenting self-efficacy (Hastings & Brown, 2002; Heller, 1993). Other studies addressing parent self-efficacy as an outcome operationalize self-efficacy as parental competence. These studies indicate that mothers who care for a child with a disability report greater competence than mothers who care for a

typically developing child (Halday & Hanzik, 1990). In one study by Stoneman and Crapps, (1988), social support is found to be a predictor of mothers' perceived competence in caring for a child with a disability (Stoneman & Crapps, 1988).

The current work examining the relation between support and caregiver well-being (e.g., life satisfaction and parenting self-efficacy), and support and family quality of life, is comprehensive and useful for service providers to develop more effective practices. However, there are certain limitations to this work that must be addressed. First, of the studies examined above, only a few (e.g., Dunst and colleagues) examine the specific types and sources of service provider support that are most useful to families. Within these studies, although researchers differentiate between participatory and relational support, the specific types of supports are based upon the unique roles and responsibilities of the service provider. Similarly, most of the studies are fundamentally focused on understanding how service provider support relates to individual or family well-being. As Trivette and colleagues' (1996) findings illustrate, more studies are needed to examine, mobilize, and capitalize upon different types of support that may come from other sources (e.g., the family) and that may be more useful to families with children with disabilities. Finally, the samples used in each of the studies examine primarily a White, low to middle-class population. Only one study had a small sample of families in poverty (i.e., Trivette, et. al., 1996). There is a dearth of research that examines these concepts, particularly within Latino families with children with disabilities.

### **Support for Latina Mothers Who Care for a Typically Developing Child**

Latino families are among the largest, youngest, and most rapidly growing groups with one of the country's highest birth rates (California Department of Health Services, 2005). According to the California Department of Health Services, in 2000, Latina women gave birth to 257,958 babies as compared to White women, who gave birth to 168,233 babies. For every birth of a white child there were 1.53 births of a Latino child. In 2005, Latina mothers gave birth to 282,823 babies as compared to White mothers, who gave birth to 155,900 babies (California Department of Health Services, 2005). For every birth of a White child there were 1.81 births of a Latino child.

The number and size of Latino families in the U.S. is growing rapidly. These families may experience higher levels of stress in caring for their children due to limited resources (e.g., language barriers, poverty, immigrant status) or different childrearing values. For example, a family that recently immigrated to the US may have a limited family support network available, as many caregivers who immigrate here do so with only a few family members. Furthermore, caregivers may value certain support activities differently. For example, a caregiver may focus on performing non child-centered activities (e.g., cooking, washing dishes, doing laundry) with the belief that the child's teacher or service provider is responsible for engaging the child in child-centered activities (e.g., helping child with homework, reading with child, organizing playdates with peers) (Bailey, et. al., 1999; Goldenberg & Gallimore, 1995). As the Latino

population continues to increase, careful examination of the unique types of support that mitigate parents' stress is necessary to enhance child and family outcomes.

Sherraden and Barrera (1997), in their qualitative study of 41 first and second generation Mexican mothers, found that families play a crucial role in providing support to these women. Family support, exemplified by care, guidance, and assistance, is often the key resource for these women, particularly during pregnancy. However, the utility of family support was only effective when the mothers had developed a long-lasting relationship with family members that began during childhood or adolescence. Furthermore, socioeconomic status affected the amount and type of family support that was provided. Families who were struggling economically provided less support as they had fewer resources, whereas families who were more secure economically provided more support as they had more resources (Sherraden & Barrera, 1997). These supports led to better economic mobility for these families.

In another study by Prelow and colleagues (2010) with his sample of 535 Latina mothers of young adolescents, he found that ecological risk influenced the mother's parenting behaviors by increasing mothers' psychological distress. However, when mothers reported having a social network of support, ecological risk had a weaker relationship to mother's psychological distress. In other words, the mothers' social network buffered the negative psychological distress stemming in part from living in a high crime neighborhood (Prelow, Weaver, Bowman, Swenson, 2010). Thus, family support, with family members that are a constant presence, can be an effective tool to ameliorate psychological distress among Latino parents who care for a typically developing child.

### **Relation Between Support and Well-being for Latino Families with Children with Disabilities**

As discussed above, having a child with a disability is particularly stressful for parents (Olsson & Hwang, 2001, 2002; Stores, et al., 1998). Latino families in particular experience more stress than non-Latino families who care for a child with a disability (Blacher et al., 1997; Magaña et al., 2004). Most of the research on Latino families with children with disabilities that examines the relation between caregivers' perceptions of support and individual and family well-being is not grounded within a theoretical perspective. The following review will identify a few key findings that summarize the current literature on Latino families and their children with disabilities and the relation between perceptions of support and caregiver and family outcomes.

First, Latino families may lack access to social services that are crucial to the healthy development of their child with a disability. For example, these families are at increased risk for lack of access and underutilization of crucial intervention services (Arcia, Keyes, Gallagher, & Eric, 1993; Ginsberg, 1992), reduced participation in planning and coordinating services (Sontag & Schacht, 1994), and difficulty participating in parent support programs (Heller, Markwardt, Rowitz, & Farber, 1994; Shapiro & Simonsen, 1994). Other Latino families also perceive limited access to such formal supports. For example, Bailey and colleagues (1999) examined 200 Latino

families with children with disabilities to understand what types of formal supports are useful to them. They found that some Latino families are not aware of the types of services that are necessary for their children (Bailey, et. al., 1999). Although these characteristics are key elements in early intervention to promote successful child and family outcomes, some Latino families may use different methods for accessing and utilizing support and may value different support networks to nurture their child's development and maintain their sense of well-being. Thus researchers must examine the specific types and sources of supports that are useful to Latino families in order to adapt service provision in a manner that is appropriate for these families.

Second, Latino families may or may not be less satisfied than non-Latino families with the amount of or quality of services they receive. Current research provides contradictory findings regarding the extent to which Latino families feel a sense of support from service providers caring for their children. Some studies find that Latino parents are likely to view members of the formal support network as having the specialized expertise needed to address their child's needs (Bailey et. al., 1999) and are less likely to access support from family and friends (Magaña, 1999). Other studies have found that Latino parents experience formal support as being just as satisfactory as familial support (Bailey, et. al., 1999; Steinberg, et. al., 1997). For example, in their qualitative study of 200 Latino families with children with disabilities living in the United States (from Puerto Rico and Mexico), Bailey and colleagues (1999) found that families reported professional support to be generally helpful to them and their children with disabilities, but also they found equally high levels of support among members of the immediate family, who helped to buffer some of the family stress caused by having a child with a disability (Bailey, et. al., 1999).

Other research points to the perception of discriminatory practices by teachers or service providers and its effect on the trust that Latino families have in these institutions (Larson, 1998; Shapiro, Monzó, Rueda, Gomez, & Blacher, 2004). For example, in a focus group study, 16 Latina mothers of young adults with developmental disabilities reported that teachers and other service providers perceived them as less knowledgeable than their non-Hispanic White counterparts and expected less from them because of their ethnicity (Shapiro, et al., 2004). Furthermore, research also shows that Latino families who are aware of the types of services that their child needs, were primarily dissatisfied with those services (Bailey, et. al., 1999). Those families who were dissatisfied with their services were so for the following reasons: (a) poor communication with service providers (doctors, teachers) due to language differences (e.g., letters were written in English, translators were generally unavailable); (b) a lack of information about their children's disabilities or the services that are available; and (c) feeling discrimination because of their ethnicity (Heller, et al., 1994; Bailey, et. al., 1999; Larson, 1998; Shapiro, et. al., 2004). These discriminatory practices that lead to a lack of trust in the formal supports and services and may also lead some Latino families to rely more heavily on familial support.

Third, when they do have access to support, Latina mothers in particular, have better psychological outcomes. One study found that Latina mothers who have access to formal sources

of support (e.g., child's teachers and therapists) have lower rates of depression (Blacher, et al., 1997). Social support is particularly important for Latina mothers' mental health (Aranda & Knight, 1997; Keefe, et al., 1979; Sabogal, et al., 1987). Family support, in particular, has been shown to reduce the effects of stress and prevent mental illness for Latina mothers who care for a child with a disability (Keefe, et al., 1979).

As is evident above, service provider support for Latino families with children with disabilities may be ineffective in promoting the healthy adaptation of these families. Thus it is important to explore other types of support that may be more effective for Latino families with children with disabilities. Informal or familial support has been perceived as valuable to Latino families, particularly for the mental health of Latino caregivers (Aranda & Knight, 1997; Baca Zinn & Wells, 2000; Keefe, et al., 1979). Some Latino parents feel that family members are better able to understand and provide care for their child with disabilities than are service providers (García, Pérez, Ortiz, 2000; Garwick, et al, 1998; Harry, 1992; Lobato, Kao, & Plante, 2005; Rehm, 2000). For example, a qualitative study of ethnically diverse families with mentally ill family members found that Latino families declined to seek outside help for their mentally ill family member based on the belief that it was the family's obligation to care for the family member at home (Guarnaccia, Parra, Deschamps, Milstein, & Arguiles, 1992).

Another multi-method study by Keefe and colleagues (1979) compared the social support networks of Mexican-American and Anglo-American families who care for a child with a disability and found that the primary differences between the two ethnic groups is that the Anglo-American group had a tendency to capitalize upon their relationships with informal, non-family supporters (e.g., friends, neighbors), whereas the Mexican-American group primarily relied on their kin networks for support (Keefe, et al., 1979).

More recent studies have also found that Latino families utilize familial support more readily than formal support. For example, Correa and colleagues (2010), in their qualitative study, examined the support systems of 25 Puerto Rican, low-income, single mothers who care for a child with a disability, to understand the types of familial support available to them. They found that family members (both immediate and extended) were the main sources of support for these families. Specifically, maternal grandmothers and aunts played particularly salient roles in providing instrumental and emotional support (Correa, Bonilla, & MacPherson, 2010).

### **Culturally Situated Beliefs - Familism**

As is evident from the current literature, the structural risk factors present in some Latino families do not fully explain why Latina mothers experience more stress than non-Latina mothers who care for a child with a disability. Thus, there may be certain culturally situated beliefs regarding disability and family that may further explain why Latina mothers experience more stress and depression than non-Latina mothers who care for a child with a disability.

Some Latino families hold certain culturally situated beliefs pertaining to family cohesiveness and individual family obligations that may be useful for understanding how social support functions within this population (Correa, et. al., 2010; Magaña, 1999). Attitudinal familism, a value considered distinctly Latino, is the belief in the commitment of family members to their family relationships. It emphasizes the importance of family closeness, family obligation to assisting its members, and family member responsibility for the well-being of the entire family (Cauce & Domenech-Rodriguez, 2002).

Steidel & Contreras (2003), defined four components that make up attitudinal familism and used these components to develop a scale to formally measure attitudinal familism. The first component is the belief that family comes before the individual. According to this notion, individuals should sacrifice their own desires and needs for those of the family, because the outcomes of the family are most important. The second component of attitudinal familism is the concept of family interconnectedness. The premise is that family members must keep a close, emotional and physical bond with other family members although they may be independent in other aspects of their life. The third component of attitudinal familism involves the belief in familial support in times of need. Family members should expect and provide support when they perceive other family members are experiencing difficult circumstances. The fourth component of attitudinal familism is the belief in family honor. According to this idea, family members must protect the family name and the family's reputation (Steidel & Contreras, 2003).

In recent studies that have compared the levels of attitudinal familism between Latinos and non-Latinos, Latinos were significantly more likely to endorse attitudinal familism than non-Latinos (Sabogal, Marín, Otero-Sabogal, Marín, Perez-Stable, 1987). In other studies examining the relation between acculturation and attitudinal familism among Latinos only, despite varying levels of acculturation, Latino individuals retain a strong level of attitudinal familism (Cortes, 1995; Rodriguez & Kosloski, 1998). Thus, the strong endorsement of attitudinal familism among Latino individuals may affect how Latina mothers perceive the relation between his or her perceptions of familial support and his or her family well-being in caring for a child with a disability.

This concept of attitudinal familism, that is partly defined by individuals physically and emotionally supporting their family members in times of need, may explain why Latino families expect family support. Due to the value placed on different support activities within the family's home country, Latino families may value certain support activities differently. For example, a caregiver may focus on performing non child-centered activities (e.g., cooking, washing dishes, doing laundry) with the belief that the child's teacher or service provider is responsible for engaging the child in child-centered activities (e.g., helping child with homework, reading with child, organizing playdates with peers) (Bailey, et. al., 1999; Goldenberg & Gallimore, 1995). Therefore, understanding the unique familial supports available to Latino families with children with disabilities is useful and necessary to provide individualized and effective services to these families.

Latino families have a strong sense of attitudinal familism, which may affect both the type and sources of familial support that they expect. For example, caregivers may expect to receive support from a variety of sources (e.g., siblings, grandparents, aunts, partners) and may not expect partners to provide more support than more distant relatives (Cauce & Domenech-Rodriguez, 2002, Steidel, & Contreras, 2003). Furthermore, the support of several family members may compensate for the lack of financial resources available to some families (Baca Zinn, & Pok, 2002). Therefore, for Latino families, the source of perceived support -- whether it be from a partner or from a different family member -- may not be as important as it may be for non-Latino families.

In the current study, I examine how familism moderates the relation between familial support and family well-being. More specifically, I am interested in understanding whether a caregiver's level of familism in combination with his or her perception of the familial support he or she receives, is related to his or her well-being (i.e., family quality of life, life satisfaction, and parenting self-efficacy). I expected that caregivers who perceived that they had more familial support would report a higher sense of family well-being. I also expected that caregivers who reported higher levels of attitudinal familism would report a higher family quality of life. Additionally, I expected that mothers who strongly endorsed familism and who perceived that they had abundant family support would express a particularly strong sense of well-being. Early social psychology literature suggests that when there is a match between a parent's preference and his or her actual situation, the individual is likely to be satisfied with his or her situation and better able to act effectively in the parenting role (Everson, Sarnat, & Ambron, 1984).

In this study, if caregivers' expectations of family support and their levels of actual familism characteristics match, they may be more likely to have a higher family quality of life. However, caregivers who report high expectations of family support but do not perceive the provision of that support, may be particularly dissatisfied with their family quality of life relative to those individuals who have lower expectations of family support.

## **The Current Study**

Although the current research differentiates among the types of supports (i.e., formal, informal, or familial support) that are useful to Latino families, it does not clearly identify the source of that support. Therefore it is difficult to separate the supporter from the supporting activity. For example, studies may conclude that formal support is more useful to families, but the measures used do not identify the provider of the formal support and do not specify the type of formal support activity. As the current research neither identifies the sources of support (e.g., who in the family supports the caregiver) nor specifies the specific type of support (e.g., emotional or instrumental) that buffers the negative effects connected with caring for a child with a disability, my study aims to discover the specific types and sources of support that are useful to Latino families with children with disabilities. I will use two different measures of perceived support (i.e., emotional and instrumental) to examine how each type of support relates to a caregiver's well-being and a family's quality of life. Perceived emotional support – the

perception of reassurance and nurturance from others – measures the perceived adequacy of support (the quality of the support) (Barrera, 1986). Perceived instrumental support – the perception of tangible assistance from others – measures the perceived availability of support (the availability of family members in providing support) (Taylor, Sherman, Kim, Jarcho, Takagi, & Dunagan, 2004).

In addition to the poorly defined support terms in the current literature, there are several other limitations of the current literature examining Latino families with children with disabilities. First, the majority of the studies are qualitative with small sample sizes, limiting the generalizability across larger samples. Also, the research simply identifies and describes the general types of support that are useful to Latino families with children with disabilities (e.g., formal, informal, familial). There is minimal research that interprets the relationship between support and family or child outcomes (e.g., caregiver wellbeing) (Blacher, et al., 1997). Furthermore, the current research does not account for the fact that perceived support may have a greater influence on psychological well-being than enacted support. The present study will attempt to add to the literature on social support by addressing these issues.

In a recent review of the literature examining families with children with disabilities, Canary (2008), describes the current research as clearly illustrating a relationship between support and positive family outcomes (Canary, 2008). In order to further develop this field, she calls for future research to examine *how* support relates to family well-being. The proposed study responds to this call and addresses the above limitations of the current research by identifying specific types and sources of familial support that may relate to a family's well-being. First, I examined the measure of perceived support as it is shown to be more effective than enacted support (Taylor & Lynch, 2004). Second, I created variables that define specific types and sources of perceived familial support that may be useful to families. Third, I examined the relation between these specific supports and family well-being as measured by family quality of life, a caregiver's satisfaction with life, and a caregiver's self-efficacy. Finally, I examined whether culturally situated beliefs (i.e., familism) moderate the relation between perceived support and caregiver well-being or family quality of life for these families.

Specifically this study examined the perceptions of emotional and instrumental support reported by 146 mothers with children with intellectual disabilities. In the course of the study, the following research questions were explored:

1. How do Latina mothers and non-Latina mothers compare with respect to the following types and sources of perceived support?

Amount of:

- a. Child-centered instrumental support provided by the partner.
- b. Non child-centered instrumental support provided by the partner.
- c. Child-centered instrumental support provided by other family members.
- d. Non child-centered instrumental support provided by other family members.
- e. Emotional support provided by the partner.



f. Emotional support provided by other family members.

2. For Latina mothers and for non-Latina mothers, what is the relation among the types and sources of support (as described in RQ1) and the following indicators of family well-being: family quality of life, a caregiver's sense of self-efficacy, and a caregiver's satisfaction with his or her life?

3. For Latina mothers and for non-Latina mothers, to what extent is familism related to family and caregiver well-being? Does it contribute significantly to the prediction of family and caregiver well-being above and beyond the contribution of perceived support? Does familism moderate the relationship between perceived support and family or caregiver well-being as exemplified through the following outcome variables: family quality of life, parenting self-efficacy, and a caregiver's satisfaction with his or her life?

## CHAPTER TWO

### Method

#### Participants

The sample was drawn from a larger data set composed of 200 family members who cared for children with intellectual disabilities. As the current study is focused on understanding the types and sources of support available to the caregiver from family members living in the household, including partners, I chose to include only mothers who were married or living with a partner. The final sample includes 146 mothers. Participants reported the mean age of the children was 6.00 years ( $SD = 2.29$ ). Table 1 shows selected demographics of the mother and child sample. The majority of the children were male (67%) and they had a variety of intellectual disabilities including autism, Down syndrome, cerebral palsy, mental retardation, or a combination of disorders.

The mothers in the sample had a mean age of 36.00 years ( $SD = 6.60$ ). Mothers' ethnicity was categorized into two groups: Latina or non-Latina. Most of the participants identified as either Latina (57.50%) or White/Caucasian (25.00%). The remaining participants identified as Asian (9.60%) (e.g., Filipino, Chinese), Black or African American (4.10%), or other (3.40%). The final sample yielded 84 participants who identified as Latina and 62 participants who identified as non-Latina.

Of the 146 mothers in the sample, 90 were not employed outside the home (61.60%), and 56 were employed full or part-time outside the home (38.40%). Ninety-two mothers were not born in the U.S. (63.00%), and 54 were born in the U.S. (37.00%). Of the final sample, 75 mothers spoke Spanish in the home (51.40%), and 71 mothers spoke English or another language in the home (51.00%).

Less than one percent of mothers identified as having no formal schooling; 17.30% of mothers identified as having had 11 years of schooling or less; 24.10% of mothers identified as having graduated from high school; 23.40% of mothers identified as having some college or vocational school experience; 19.30% of mothers identified as having a bachelor's degree; and 15.90% of mothers identified as having a graduate or professional degree. Because many participants had been educated outside of the U.S. it was not feasible to use participant's education level as a continuous variable. The final sample yielded 60 mothers (41.00%) who had less than a high school degree, and 85 mothers (59.00%) who graduated high school or who completed some college or graduate school.

Twenty-eight mothers identified their family income as under \$15,000 annually (20.90%). Forty mothers identified their family income as between \$25,001 and \$50,000 (29.90%). Thirty-one mothers identified their family income as between \$50,001 and 100,000 (23.10%). Thirty-five mothers identified their family income as over \$100,000 (26.10%). The family income level for the final sample was between \$35,001 and \$50,000 per year.

Table 1: *Mother and Child Demographic Characteristics*

Demographic Characteristic	Latina Mothers (n = 84)	Non-Latina Mothers (n = 62)	Total Sample (n = 146)
<b>Participant Level Variables:</b>			
Mean age	33.72	39.05	35.91
Education level completed			
Less than high school graduate	25 (30.10%)	0 (0.00%)	25 (17.30%)
High school graduate	30 (36.10%)	5 (8.10%)	35 (24.10%)
Some college	17 (20.50%)	17 (27.40%)	34 (23.40%)
Bachelor's degree	11 (13.30%)	17 (27.40%)	28 (19.30%)
Graduate degree	0 (0.00%)	23 (37.10%)	23 (15.90%)
Employed (full or part time)			
Yes	17 (20.20%)	39 (62.90%)	56 (38.40%)
No	67 (79.80%)	23 (37.10%)	90 (61.60%)
Immigrant to the U.S.			
Yes	77 (91.7%)	15 (24.2%)	92 (63.00%)
No	7 (8.30%)	47 (75.80%)	54 (37.00%)
Main Language Spoken at home			
Spanish	74 (88.10%)	1 (1.60%)	75 (51.40%)
English	10 (11.90%)	55 (88.70%)	65 (44.50%)
Other	0 (0.00%)	6 (9.70%)	6 (4.10%)
Annual Household Income Level			
Under \$25,000	26 (33.30%)	2 (3.60%)	28 (20.90%)
Between \$25,001 - \$50,000	35 (44.9%)	5 (8.90%)	40 (29.90%)
Between \$50,001 - 100,000	14 (17.90%)	17 (30.40%)	31 (23.10%)
Over \$100,000	3 (3.80%)	32 (57.10%)	35 (26.10%)
<b>Child Level Variables:</b>			
Mean age	5.74	7.19	6.35
Child Functioning Level: Does X play well with others?			
Yes	49 (58.30%)	41 (66.10%)	90 (61.60%)
No	35 (41.70%)	21 (33.90%)	56 (38.40%)
Type of Disability			
Autism	38 (45.20%)	32 (52.50%)	70 (48.30%)
Other intellectual Disability	46 (54.8%)	29 (47.50%)	75 (51.70%)
Child Gender			
Male	56 (66.70%)	42 (67.70%)	98 (67.10%)
Female	28 (33.30%)	20 (32.30%)	48 (32.90%)

## Chi-Square Analyses

Chi-square analyses were conducted to determine whether there were any significant differences between the Latina and non-Latina mothers with respect to the participant's demographic variables. Table 2 illustrates the results of the chi-square analyses. There were significant differences between Latina and non-Latina mothers with respect to education ( $X^2 = 49.56, p=0.00$ ), employment status ( $X^2 = 27.46, p<0.00$ ), immigrant status ( $X^2 = 69.68, p<0.00$ ), main language spoken at home ( $X^2 = 106.80, p<0.00$ ), and annual household income ( $X^2 = 56.30, p = 0.00$ ). Non-Latina mothers were more likely to report being more educated, being employed, and having a larger annual household income than Latina mothers. Latina mothers were more likely to report being unemployed, immigrants who primarily spoke Spanish, as compared to non-Latina mothers who were primarily employed, non-immigrants, and spoke English. Child demographic variables were also assessed with chi-square analyses and did not reveal significant results. A t-test was also conducted to examine if there were significant differences between Latinas and non-Latinas regarding child age, and no significant differences were found.

## Procedures and Measures

Participants were recruited from three sources: a large teaching hospital in San Francisco, a non-profit corporation that provides services and supports to children and their families with disabilities, and through local support groups and conferences for families with children with disabilities. The non-profit corporation yielded a 23.00% response rate and the teaching hospital yielded a 35.00% response rate. Of the 146 total families in the study, 13.00% (19) came from the large teaching hospital, 76.00% (111) came from the non-profit organization, and 11.00% (16) came from other sources (i.e., support groups, or disability conferences).

These institutions searched their records and identified families who had a child between the age of three and 10 with an intellectual disability. The institutions used the DSM-IV to define an intellectual disability (American Psychiatric Association, 1994). The definition of intellectual disability includes two components: (a) below average intellectual functioning as defined by an IQ score of 70 or below; and (b) deficits or impairments in current adaptive functioning (e.g., not meeting developmental milestones for his/her age), in at least two of the following areas: communication, self-care, social skills, use of community resources, self-direction, functional academic skills, work, leisure, health issues, and safety (American Psychiatric Association, 1994). The institutions also identified families who spoke primarily English or Spanish. Based on their initial intake interview with the family, the institutions' records indicated whether the family's primary language was English or Spanish. For the current study, the caregiver was expected to speak either English or Spanish well enough to participate in a telephone interview.

To recruit families associated with the large teaching hospital in San Francisco, recruitment letters were sent to families identified from patient records in pediatric clinics at the hospital as having a child with a moderate to severe intellectual disability. For the non-profit

Table 2: *Chi-Square Results of Relevant Mother Demographic Variables*

	Latina Mothers	Non-Latina Mothers	Chi-Square Statistic
<b>Education</b>			
Less than a high school graduate	5 (8.10%)	55 (65.50%)	49.56***
High school graduate and beyond	57 (91.9%)	28 (33.30%)	
<b>Employed (full or part time)</b>			
Yes	17 (20.20%)	39 (62.90%)	27.46***
No	67 (79.80%)	23 (37.10%)	
<b>Immigrant to the U.S.</b>			
Yes	77 (91.70%)	15 (24.20%)	69.68***
No	7 (8.30%)	47 (75.80%)	
<b>Main Language Spoken at home</b>			
Spanish	74 (88.10%)	1 (1.60%)	106.80***
English	10 (11.90%)	61 (98.40%)	
<b>Annual Household Income Level</b>			
\$50,000 or less	61 (72.60%)	7 (11.30%)	56.30***
\$50,001 or more	17 (20.20%)	49 (79.00%)	

*Note: Numbers represent actual counts of mothers in each category.*

†p< 0.10 \*p<0.05 \*\*p<0.01 \*\*\*p<0.00

organization, eligible families were sent a recruitment packet, which included a letter describing the study and an opt-in card. If the individual was interested in participating in the study, he or she returned the opt-in card in the self-addressed stamped envelope.

In addition, 16 families were recruited at conferences or support groups. At the conference, researchers set up a booth during the information portion of the conference and presented information about the study to families. If families showed interest in participating and they met the above criteria, they were asked to write their name and address on a list. In the support groups, researchers gave a short presentation describing the study to the support group members. If a support group member was interested in the study, he or she wrote his or her name and address on a list. Researchers sent recruitment packets to interested families from the conference and the support groups. Research assistants then called all interested participants, described the study in detail, and invited families to participate.

Researchers contacted by telephone each primary caregiver who had indicated an interest in participating. At the beginning of the telephone interview, the researcher read a one page consent agreement, which described the study and explained the commitment that is required of the participant. If the participant provided verbal consent to participate in the study, the researcher invited the participant to commence the interview at that time. If the participant was unable to participate in the interview at that time, the researcher and participant set up a more convenient time to complete the interview.

The 45-minute interview consisted of 19 open-ended questions (e.g., “What is the name of your child’s disability?”) and 144 Likert-style questions (e.g., Question: “Can X play well with others?” Answer choices: “Yes,” “Somewhat,” “No,” or “Don’t Know”). For many of the open-ended questions, if the participant and the researcher had developed a good rapport, the participant expanded upon his or her answer, which sometimes led to a longer interview session. If the question was a Likert-style question (e.g., “Can X play well with others?”), the researcher would first read the question and all of the answer choices before requesting a response from the participant. If the participant did not understand the question, or did not remember all or some of the answer choices, the researcher would then repeat the question and the answer choices and would then request a response from the participant. At the end of the interview, the researcher confirmed the participant’s mailing address and then sent the participant a handwritten thank-you card, along with a \$25.00 gift card as remuneration for participation in the study.

## **Independent Measures**

Based on my current research questions, I chose to include certain demographic variables in my subsequent regression analyses. These demographic variables were modified to adhere to certain statistical rules inherent with a linear regression analysis. The following discussion details the specific adaptations that were made to the demographic variables.

***Child demographic variables.*** Identifying the child’s disability diagnosis was an important variable for this study. I chose to control on whether the child has autism, as this was the most prevalent disability from our sample. This variable came from an open-ended interview question that asked participants to identify the focal child’s disability. Participants “wrote-in” the disability with which their child was diagnosed. Researchers created a list of the disabilities that were mentioned, which resulted in a 9-category variable that described the most prevalent intellectual disabilities in the sample. From this variable, I created a dichotomous variable to differentiate the participants who had a child with autism, or autism and another disability, from the participants who had a child with a different intellectual disability (e.g., Down syndrome). For the participants who responded that they had a child with autism, their responses were coded as “1,” and for the participants who responded that they had a child with another intellectual disability, their responses were coded as “0.”

In addition to examining the child’s disability, I also chose to examine the child’s functioning level by using an interview question that evaluates the child’s social engagement, a deficit in most children with autism. The question from the interview was: “Can [child] play well with others?” The distribution of this question was bimodal; therefore it was converted to a dichotomous variable. Answer choices 1 (no) and 2 (somewhat) were converted to 0 = child does NOT play well with others, and answer choice 3 (yes) was converted to 1 = child plays well with others.

***Participant demographics variables.*** The mother’s ethnicity was determined by the following question: “What is your race/ethnicity?” Participants chose one ethnicity from eight different ethnicities/races (i.e., Chinese, Filipino, Other Asian or Pacific Islander, Black or African American, Latino or Hispanic, Native American or Indigenous Person, White or Caucasian, and Refuse to Answer). Participants could identify up to four different ethnicities with which they identified, but no participants in this sample identified with more than one ethnicity/race. As my primary interests lie in examining the differences between Latinos and non-Latinos, and as most of the participants identified as either Latino or White/Caucasian, I created a dichotomous variable to differentiate between the mothers that identified as Latino and the mothers that identified with the other ethnic categories (non-Latino). The mothers responses that corresponded with Latino or Hispanic were coded as “1,” and named “Latino,” and the mothers responses that corresponded with White, Caucasian, Chinese, Filipino, Other Asian or Pacific Islander, Black or African American, or Native American or Indigenous Person were coded as “0,” and named “non-Latino.”

Mother’s immigrant status and main language spoken in the home were also modified to reflect the goals of the study. Specifically for main language spoken in the home, the interview question asked: “what is the main language you speak at home?” Mothers selected one of three answer choices: English, Spanish, or Other. If the mother selected “Other,” she was asked to specify what other language was spoken at home. This variable was converted to a dichotomous variable. Those participants who responded that the main language spoken in the home was Spanish were given a “1,” and those participants who responded that the main language spoken

in the home was English or another language, were given a “0.” For the question regarding immigrant status, the interview question asked: “Were you born in the U.S.?” Mothers responded either “yes” or “no.” No additional modifications were made to this variable.

The variable depicting mother’s education level was changed to a dichotomous variable. Due to the large percentage of participants who were educated outside of the U.S. I felt it was not useful to compare the education level of mothers across countries, when the education system may be completely different and therefore not comparable. Using the median as a marker to divide the sample, I transformed this six-category variable into a dichotomous variable. Those participants who reported having graduated high school or completed school beyond high school were coded as “1,” and those participant’s who reported not having graduated high school were coded as “0.”

The participant’s annual family income level was also transformed. Using the median to divide the sample, I transformed the eight category variable into a dichotomous variable. Those participants’ responses that identified their annual household income as \$50,000 or less were coded as “1,” and those participants’ responses that identified their annual household income as \$50,001 or more were coded as “0.”

## **Support Predictors**

In order to fully examine the specific types and sources of support available to these mothers, I developed six different types of support indicator variables that varied by type of support (emotional vs. instrumental support and child-centered vs. non child-centered support) and source of support (partner vs. other family member). The support predictors were developed from two measures, the Daily Accommodations Measure and the Kessler Perceived Support Measure.

***Daily Accommodations Measure.*** The Daily Accommodations Measure was created specifically for this study. It consists of a list of 23 daily activities and family responsibilities. In the interview, the participant is asked to identify the family member responsible for completing each activity. For example, the researcher first would introduce the set of questions by saying: “Now I am going to mention some activities from daily life. Think about your household in the last week. For each of the activities I mention, can you tell me who - if anyone - usually does that thing?” The researcher then asks the question: “Who does the cooking?” The participant would respond by identifying the family member who most commonly does the cooking at home. The researcher would then ask, “is there anyone else who does the cooking?” The participant would then, if applicable, respond with a second family member who also cooks meals. The researcher would continue asking this question until the participant's response was "no." At that point, the question was complete and the researcher would then move to the next activity. Of the 23 total questions in the measure, three questions pertaining to job accommodations were eliminated as many of the participants were not employed.



In order to understand the types and sources of support that are available to these families, I developed four instrumental support indicator variables from this measure: *partner child-centered instrumental support*, *partner non child-centered instrumental support*, *other family member child-centered instrumental support*, and *other family member non child-centered instrumental support*. These four support variables are differentiated by the type of support (i.e., child-centered vs. non child-centered), and the supporter (i.e., partner vs. other family member). To provide a clear definition of the four support indicator variables and how they were constructed, I will first define the type of support in this measure, then define how the supporters were identified in this measure, and finally how the support variables were constructed. Figure 1 and 2 illustrate the specific interview questions that correspond to each support indicator variable.

The two child-centered instrumental support indicator variables include activities where the supporter is required to interact with the child (e.g., helping the child with homework, playing with the child) and activities where the supporter is required to interact with the child's service providers or healthcare professionals (e.g., engaging in a parent-teacher conference, taking a child to a doctor's appointment). These activities are defined as child-centered because they prominently involve interactions with or about the child.

The two non child-centered instrumental support indicator variables consist of daily home activities that keep the household running smoothly (e.g., washing the dishes, doing the laundry, going grocery shopping), and information gathering activities (e.g., attending meetings or classes about the child's disability, attending parent support groups). These activities are defined as non child-centered because they do not prominently involve the child.

Not only were the four support indicator variables defined by the type of support, but also they were defined by the type of supporter providing the support (i.e., partner or other family member support). For each activity, mothers were asked to identify who in the household usually performed that activity (i.e., partner, the child's siblings, a grandparent). Mothers could mention more than one family member for each activity.

To construct the partner child-centered instrumental support indicator variable, I summed the number of child-centered support activities in which the partner was said to participate. To construct the other family member child-centered instrumental support indicator variable, I summed the number of child-centered support categories in which a non partner was said to

Figure 1: *Definitions of Instrumental Support Indicators*

Instrumental Support Indicator	Definition of Support Indicator	Questions From Interview Used to Construct Support Indicator
Partner Child-Centered Instrumental Support	The partner engages in support activities that prominently involve interactions with the child or interactions with the child's service providers (e.g., teachers, healthcare providers).	Who helps feed X or watches him/her while he or she is eating? Who disciplines X? Who plays with X? Who keeps an eye on X at home? Who helps X with learning or school activities?
Other Family Member Child-Centered Instrumental Support	Other family members (e.g., the child's siblings or grandparents) engage in support activities that prominently involve interactions with the child or interactions with the child's service providers (e.g., teachers, healthcare providers).	Who organizes play times for X with friends? Who makes X's medical and therapy appointments? Who takes X to these appointments? Who talks to the therapists and teachers about X? Who makes decisions about X's medical and educational services?
Partner Non Child-Centered Instrumental Support	The partner engages in support activities that do not directly involve the child. These activities involve managing the family's daily routine (e.g., going grocery shopping) and participating in activities within the larger community (e.g., attending a support group).	Who does the cooking? Who washes the dishes? Who does the household and/or car maintenance and repair? Who does the grocery shopping? Who buys X's clothes? Who does the laundry? Who cleans the house? Who, if anyone goes to meetings or classes about X's disability, or belongs to a parent support group?
Other Family Member Non Child-Centered Instrumental Support	The other family member (e.g., the child's sibling or grandparents) engages in support activities that do not directly involve the child. These activities involve managing the family's daily routine (e.g., going grocery shopping) and participating in activities within the larger community (e.g., attending a support group).	Who if anyone does reading about X's disability? Who if anyone talks with family and friends about how to help X?

*Note.* The answers to the interview questions were used to differentiate between Partner and Other Family Member Support.

Figure 2: *Definitions of Emotional Support Indicators*

Emotional Support Indicator	Definition of Emotional Support Indicator	Questions from Interview used to Construct the Variable
Partner Emotional Support	The partner provides reassurance and nurturance regarding childrearing.	My husband/partner listens to me if I need to talk about my worries or problems concerning X.
Other Family Member Emotional Support	The other family member provides reassurance and nurturance regarding childrearing.	My parents or inlaws listen to me if I need to talk about my worries or problems concerning X. My other relatives listen to me if I need to talk about my worries or problems concerning X.

participate.<sup>2</sup> For example if Participant A reported that her partner engaged in 7 out of the 10 child-centered instrumental support activities, Participant A's score for partner child-centered instrumental support would be 7. If Participant A reported that the other family members living in the household (e.g., the child's grandparents, siblings, etc.) engaged in 4 out of the 10 child-centered instrumental support activities, Participant A's score for other family member child-centered instrumental support would be 4.

The partner non child-centered support indicator variable and the other family member non child-centered support indicator variable were constructed in a similar fashion based on the ten non child-centered activities. For example, if Participant B reported that her partner engaged in 3 out of the 10 non child-centered instrumental support activities, Participant B's score for partner non child-centered instrumental support would be 3. If Participant B reported that other family members (e.g., the child's siblings, a grandparent, etc) engaged in 7 out of the 10 non child-centered activities, Partner B's score for other family member non child-centered instrumental support would be 7. Thus, these variables were defined by the number of activities in a specific category that are performed by a particular person or a category of persons (i.e., other family members).

***Kessler's Perceived Social Support Measure.*** Kessler's Perceived Social Support Measure is a 19-item self-report scale of perceived social support that measures a participant's perception of reassurance and nurturance from family members and friends (Kessler, 1992). I retained 15 items that primarily examine the participant's perceptions of partner and other family member's emotional support. There were two stem questions pertaining to support and the respondents indicated the extent to which various people provided support in that area. For my study I focused on the stem questions pertaining to both emotional and family member support ("My partner listens to me if I need to talk about my worries or problems concerning [child]." "My parents or in-laws listen to me if I need to talk about my worries or problems concerning [child]"). The original measure had a five-point Likert scale (1= not true at all, to 5=very true). To minimize the participant's difficulty in remembering five response options, I shortened the original Likert scale from five points to three points (1 = not true, 2 = somewhat true for me, or 3 = true).

To construct the partner emotional support indicator variable, I used the responses to one question relevant to partner emotional support (i.e., "my partner listens to me if I need to talk about my worries or problems concerning [child]"). The distribution of this question was bimodal therefore it was converted from a continuous variable to a dichotomous variable. I combined answer choices 1 (not true) and 2 (somewhat true) into one response, "partner is not or somewhat supportive, which was assigned the value 0. I converted answer choice 3 (true) to "partner is supportive", which was assigned the value 1.

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<sup>2</sup> The instrumental support indicator variables are counts of the number of activities in which supporters were said to have been involved, thus I did not compute internal reliability.

To construct the other family member emotional support indicator variable, I combined the two questions from the same item stem that pertained to other family members: “My parents or in-laws listen to me if I need to talk about my worries or problems concerning [child],” and “My other family members listen to me if I need to talk about my worries or problems concerning [child].” The distribution of these questions were also bimodal and it was converted from a continuous to a dichotomous variable; 1 = participants with high emotional support from other family members, and 0 = participants with low or no emotional support from other family members.

## **Dependent Measures**

The following discussion describes the three outcome variables that I chose to include in this study. One outcome examines the family’s overall quality of life (i.e., Family Quality of Life), and the other two outcomes examine the caregiver’s well-being (i.e., Individual Satisfaction with Life, and Parenting Self-Efficacy). A fourth variable, the Attitudinal Familism Scale was used as a moderator variable to understand its effect on the relationship between support and well-being.

***Beach Center Family Quality of Life Measure.*** The Beach Center Family Quality of Life Measure contains 25 items grouped into five subscales: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability Related Support (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Table 3 provides descriptive characteristics for each of the dependent measures. The original measure had a five-point Likert scale identified by three labels distributed evenly throughout the scale (e.g., 1 = not at all important, 3 = somewhat important, 5 = very important). To minimize the participant’s difficulty in remembering five response options, I shortened the original Likert scale from five points to three points and modified the answer choices so that they were similar to those answer choices available for the other survey questions. Specifically, the answer choices were adapted to correspond with a three-point Likert scale (i.e., 1 = dissatisfied, 2 = somewhat satisfied, or 3 = satisfied). Sample questions include: “How satisfied are you with the amount of time your family spends together?” “How satisfied are you with the amount of time family members have to pursue their own interests?” I eliminated three questions from these constructs due to repetition among certain questions contained in the survey. I used the first three constructs for this study (Family Interaction, Parenting, and Emotional Well-being) to measure family quality of life because I am primarily interested in understanding the psychological components of family well-being.

To construct the family quality of life variable, I computed the mean for each of the five constructs by adding up the numerical value associated with the response to each of the questions related to the particular construct and dividing by the number of questions in that construct. To

calculate the composite score based on the three constructs of interest (i.e., Family Interaction, Parenting, and Emotional Wellbeing), I calculated a mean score by adding up the numerical value associated with the response to each of the questions in the three constructs and dividing by the number of questions. The original distribution of this variable was negatively skewed. In order to control for this ceiling effect, and to simulate a larger distribution of answer choices, I conducted a cubed-root formation. Coefficient alpha for this measure was 0.87 (See Table 3).

***Satisfaction With Life Measure.*** The participant's satisfaction with life was measured using the Satisfaction With Life Scale, a five-item questionnaire pertaining to global judgments about the satisfaction of one's life (Deiner, Emmons, Larsen, & Griffin, 1985). The original measure had a seven-point Likert scale (i.e., 1=strongly disagree, 2=disagree, 3=slightly disagree, 4=neither agree nor disagree, 5=slightly agree, 6=agree, 7=strongly agree). To minimize the participant's difficulty in remembering seven response options, I shortened the original Likert scale from seven points to three points. In the interview, participants were asked to respond to each question based on a three-point Likert scale (i.e., 1 = Disagree, 2 = Agree somewhat, or 3 = Agree). Sample questions include: "In most ways my life is close to my ideal," "The conditions of my life are excellent," and "So far, I have gotten the important things that I want in life." To construct the satisfaction with life composite, I calculated the mean of the numerical values associated with each of the responses to the five satisfaction with life items. The original distribution of this variable was negatively skewed. In order to control for this ceiling effect, I conducted a square-root transformation. Coefficient alpha was 0.82 (See Table 3).

***Family Empowerment Measure.*** In order to measure parenting self-efficacy, I used 13 items from the adapted Family Empowerment Scale; a robust scale originally made to assess family's attitudes, knowledge, and behaviors on three levels: within the family, the service system, and on a broad community/political level. The original measure had 28 items. I eliminated those items pertaining to the community/political level because I am primarily interested in assessing the participant's efficacy within the family and the service system. This measure was specifically developed for families with children with disabilities (Koren, DeChillo, & Friesen, 1992). The original measure had a five-point Likert scale (i.e., 1 = not true at all, to 5 = very true). To minimize the participant's difficulty in remembering five response options, I shortened the original Likert scale from five points to three points. In the interview, participants were asked to respond to each question based on a three-point Likert scale (i.e., 1 = not true, 2 = somewhat true, or 3 = true). Sample questions include: "I feel that I have the right to approve all services my child receives," "When problems arise with my child I handle them pretty well," and "I make sure that professionals understand my opinions about what services my child needs." To construct the self-efficacy composite variable, I calculated the mean of the numerical values associated with the responses to the 13 items in the scale. The original distribution of this variable was skewed negatively. I conducted a cubed-root transformation. Coefficient alpha for this measure was 0.84 (See Table 3).

***Attitudinal Familism Measure.*** The Attitudinal Familism Scale (Steidel & Contreras, 2003) is an 18-item scale developed to measure the four constructs of Attitudinal familism: (1) Family comes before the individual; (2) Familial interconnectedness - adults should keep strong emotional and physical bonds with their family although they may be independent (e.g., live near family members); (3) Familial reciprocity in times of need; and (4) Familial honor – individuals have a duty to protect the family name and honor. Due to time constraints, I eliminated from the scale the seven questions relating to family honor. The original measure had a 10-item Likert response scale (i.e., 1 = strongly disagree, to 10 = strongly agree). To minimize the participant’s difficulty in remembering 10 response options, I shortened the original Likert scale from 10 points to three points. In the interview, participants were asked to respond to each question based on a three-point Likert scale (i.e., 1 = disagree, 2 = agree somewhat, or 3 = agree). Sample questions included: “A person should rely on his or her family if the need arises,” and “A person should often do activities with his or her immediate and extended families, for example eat meals together.” To construct the familism composite variable, I calculated the mean of the numerical values associated with the responses to the 11 items in the scale. Coefficient alpha for this measure was 0.74 (See Table 3).

To analyze the moderating effect of familism on the relationship between the six support composite variables and the outcome variables, I created interaction terms by multiplying the standardized familism score with each of the support composites. These variables were used to answer research question three.

Table 3: *Descriptive Statistics for the Major Study Variables*

Variable	M	SD	Cronbach's alpha
Family Quality of Life	16.71	7.45	0.87
Satisfaction with Life	14.89	8.43	0.82
Parenting Self-Efficacy	19.46	5.75	0.84
Familism	2.73	0.27	0.74

*Note.* The Family quality of Life and Parenting Self-Efficacy variables were cubed to account for ceiling effect. The Satisfaction with Life variable was squared to account for ceiling effect. Means for the transformed composites are provided.



## CHAPTER THREE

### Results

In the following section I describe the specific results pertaining to each of my three research questions.

#### **Research Question One: Differences Between Latina and Non-Latina Mothers Regarding Types and Sources of Support**

One purpose of this study is to understand the differences between Latina and non-Latina mothers regarding the four instrumental support indicator variables: *partner child-centered instrumental support*, *other family member child-centered instrumental support*, *partner non child-centered instrumental support*, and *other family member non child-centered instrumental support*, and the two emotional support indicator variables: *partner emotional support* and *other family member emotional support*. To understand these differences, I first examined the descriptive characteristics of Latina and non-Latina mothers among the six support composite variables.

For the emotional support indicator variables, Table 4 illustrates significant differences between Latina and non-Latina mothers on their perceived partner emotional support ( $X^2 = 5.29$ ,  $p < 0.05$ ). Latina mothers reported having less partner emotional support than non-Latina mothers. Out of the 84 Latina mothers, 58 mothers reported having partner emotional support and 26 reported having no partner emotional support. Out of the 62 non-Latina mothers, 53 reported having partner emotional support and nine reported having no partner emotional support.

Examination of the individual instrumental support items reveals that mothers experienced the most support from the partner, in child-centered instrumental activities (e.g., helping with homework). Mothers experienced the least support from other family members, in non child-centered activities (e.g., washing dishes, gathering information about the child's disability). T-tests revealed no significant differences between Latina and non-Latina mothers for the four instrumental support composite variables (See Table 5).

#### **Research Question Two: Examination of the Relations Between the Six Support Predictors and the Three Outcome Variables**

For each of the three outcome variables (i.e., family quality of life, individual life satisfaction, & parenting self-efficacy), I conducted a four-step data analysis process:

Step 1: To determine which subset of demographic control variables to include in the regressions, I analyzed relations between the full set of demographic control variables and the outcome variables through correlation and T-test analyses. I then conducted a simultaneous regression using those demographics that were associated with the outcome variables.

*Table 4: Chi-Square Results of Emotional Support Predictors*

	Latina Mothers	Non-Latina Mothers	Chi-Square Statistic
<hr/>			
Partner Emotional Support			
No support	26 (31.00%)	9 (14.50%)	5.29*
Some or a lot of support	58 (69.00%)	53 (85.50%)	
Other Family Member Emotional Support			
No support	33 (39.30%)	19 (30.60%)	1.19 (ns)
Some or a lot of support	47 (56.00%)	40 (64.50%)	

Table 5: Means of Instrumental Support Activities by Ethnicity

	Latina Mothers		Non-Latina Mothers		T-Test
	Mean	SD	Mean	SD	
Partner child-centered instrumental support	5.33	2.18	5.31	2.19	0.07 (ns)
Other family member child-centered instrumental support	3.24	2.45	3.60	3.16	-0.73 (ns)
Partner non child-centered instrumental support	4.17	2.02	4.44	2.41	-0.77 (ns)
Other family member non child-centered instrumental support	1.98	2.06	1.97	2.40	0.02 (ns)

*Note.* There were 10 total child-centered instrumental support activities and 10 total non child-centered instrumental support activities.

T-tests were conducted for all instrumental support composites; no significant differences were found.

†p< 0.10 \*p<0.05 \*\*p<0.01 \*\*\*p<0.00

Step 2: To examine the unique relations between each support predictor and the outcome variable, I conducted individual regression analyses with the final set of demographic control variables and each substantive support predictor.

Step 3: To understand the moderating effect of ethnicity on the relation between each significant support predictor (as determined in step 2) and each outcome variable, I constructed an interaction variable (ethnicityXSupport composite) and included it along with the ethnicity and the component support indicator variable.

Step 4: To understand the combined effect of the support predictors in one regression, I conducted a full regression model using all of the support variables and the demographic control variables.

First, to determine a specific set of demographic variables to include in the subsequent regression analyses, I examined the relations among the demographic variables and the three outcome variables using Pearson correlations and t-tests (see Table 6). I chose a conservative approach in selecting the demographic variables to include in the regression analyses. Rather than choosing specific demographic variables that were correlated with each outcome variable, I chose to include the demographic variables that had at least one significant correlation with any of the three outcome variables. As shown in Tables 7 and 8, family quality of life, satisfaction with life, and parenting self-efficacy were associated with six demographic variables: mother's education level, mother's ethnicity, child's gender, whether the child has autism, child's functioning level, and child's age. Mothers who reported having more education had a significantly lower family quality of life than mothers who reported not completing high school ( $t = -2.82, p < 0.01$ ). Mothers who reported having more education, reported having a significantly lower satisfaction with life than mothers who reported completing high school ( $t = -2.20, p < 0.05$ ). The relation between mother's education level and parenting self-efficacy was not significant.

For ethnicity, there was a non-significant trend in the relation between mothers who identified as Latina and mothers who reported having a higher family quality of life ( $t = 1.85, p < 0.10$ ). Mothers who identified as Latina had a significantly higher satisfaction with life than mothers who identified as non-Latina ( $t = 2.31, p < 0.05$ ). The relation between ethnicity and parenting self-efficacy and ethnicity and family quality of life was not significant.

For child gender, mothers who reported caring for a male child had a higher sense of parenting self-efficacy than mothers who reported caring for a female child ( $t = 2.24, p < 0.05$ ). There were no significant differences between child gender and family quality of life or child gender and satisfaction with life.

For autism, mothers who reported caring for a child with autism had a significantly lower family quality of life and lower satisfaction with life than mothers who reported caring for a child with a different intellectual disability ( $t = -2.67, p < 0.01, t = -2.74, p < 0.01$ ). On the other hand, there was a non-significant trend in the relation between mothers who reported caring for a

Table 6: *T-Test Results of Demographic Control Variables*

Demographic Variable	Family Quality of Life			Satisfaction with Life			Parenting Self-Efficacy		
	Mean	SD	T-Value	Mean	SD	T-Value	Mean	SD	T-Value
Mother's education:									
HS graduate	15.25	7.53	-2.82**	5.41	2.49	-2.20*	19.80	5.39	0.87
Not HS graduate	18.71	6.93		6.31	2.34		18.95	6.27	(ns)
Ethnicity:									
Latino	17.68	7.52	1.85†	6.18	2.35	2.31*	19.03	6.37	-1.11
Non-Latino	15.40	7.19		5.25	2.50		20.05	4.75	(ns)
Child's Gender:									
Male	16.23	7.91	1.19 (ns)	5.69	2.60	0.68 (ns)	18.73	5.92	2.23*
Female	17.68	6.35		5.96	2.12		20.96	5.11	
Child's Functioning Level:									
Plays well with others.	17.96	7.44	2.62**	6.08	2.40	1.88†	20.25	5.57	2.11*
Does not play well with others	14.70	7.07		5.30	2.48		18.19	5.85	
Autism									
Yes	15.09	7.57	-2.66**	5.23	2.49	-2.74**	18.56	5.60	-1.85†
No	18.32	7.02		6.33	2.31		20.32	5.82	

Note. 146 total sample

†p<0.10 \*p<0.05 \*\*p<0.01 \*\*\*p<0.001

child with autism and those who reported having a higher sense of parenting self-efficacy ( $t = -1.85$ ,  $p = 0.07$ ).

For child functioning level, mothers who reported that their child played well with others reported having a significantly higher family quality of life and a higher sense of parenting self-efficacy than mothers who perceived that their child did not play well with others ( $t = 2.62$ ,  $p < 0.01$ ,  $t = 2.13$ ,  $p < 0.05$ ). There was a non-significant trend for the relation between mothers who reported that their child played well with others, and mothers who reported having a higher satisfaction with life ( $t = 1.90$ ,  $p = 0.06$ ).

For child's age, the only continuous demographic variable, I conducted a Pearson correlation (see Table 7). There was a correlation between child's age and parenting self-efficacy ( $r = 0.21$ ,  $p < 0.01$ ), but no significant correlation between child's age and family quality of life or child's age and satisfaction with life.

These six demographic variables were included in a simultaneous OLS regression with each of the three outcome variables. Mothers who reported having a higher family quality of life, reported having less education ( $b = -0.20$ ,  $p < 0.05$ ), reported that their child plays well with others ( $b = 0.24$ ,  $p < 0.01$ ), and this model explained 11% of the variance.

Mothers who reported a higher life satisfaction, reported that their child plays well with others, ( $b = 0.17$ ,  $p < 0.05$ ), reported that their child does not have autism ( $b = -0.18$ ,  $p < 0.05$ ), and this model explained 7% of the variance.

Mothers who reported a higher sense of parenting self-efficacy reported having an older child ( $b = 0.20$ ,  $p < 0.05$ ), reported that their child plays well with others ( $b = 0.17$ ,  $p < 0.05$ ), reported having a male child ( $b = 0.18$ ,  $p < 0.05$ ), and this model explained 9% of the variance.

Second, in order to understand the behavior of each individual support predictor in the regression, I constructed individual regressions with the six demographic variables and each support variable. Examining each support predictor individually allows one to determine the unique effect that each predictor has on the outcome variable.

Regarding family quality of life, the regression analyses reveal that partner non child-centered instrumental support, other family member non child-centered instrumental support, partner emotional support, and other family member emotional support significantly predicted family quality of life after controlling for mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism. Mothers who reported having a high family quality of life reported having more partner non child-centered instrumental support ( $b = 0.19$ ,  $p < 0.01$ ), more other family member non child-centered instrumental support ( $b = 0.14$ ,  $p < 0.05$ ), more partner emotional support ( $b = 0.41$ ,  $p < 0.00$ ), and more other family member emotional support ( $b = 0.39$ ,  $p < 0.00$ ), than mothers who reported having a lower family quality of life. There was a non-significant trend in the relation between mothers who

Table 7: Correlational Analysis - Child's Age

	Mean	SD	Pearson Correlation		
			Family Quality of Life	Satisfaction with Life	Parenting Self-Efficacy
Child's Age	6.35	2.28	-0.11 (ns)	-0.07 (ns)	0.21**

*Note.* Child's age was the only continuous demographic variable thus it was the only one with a correlational analysis.

reported having partner child-centered instrumental support and their higher family quality of life ( $b = 0.14, p < 0.10$ ) (see Table 8).

Regarding satisfaction with life, the individual regression analyses revealed that partner non child-centered instrumental support, partner emotional support and other family member emotional support was significantly related to satisfaction with life after controlling for mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism. Mothers who reported having a high satisfaction with life reported having more partner non child-centered instrumental support ( $b = 0.19, p < 0.05$ ), more partner emotional support ( $b = 0.37, p < 0.00$ ), and more other family member emotional support ( $b = 0.30, p < 0.00$ ), than mothers who reported having a lower satisfaction with life. There was a non-significant trend in the relation between mothers who reported having other family member child-centered instrumental support and their higher satisfaction with life. ( $b = 0.03, p = 0.091$ ).

Regarding parenting self-efficacy, the individual regression analyses reveal that partner emotional support and other family member emotional support was significantly related to parenting self-efficacy after controlling for mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism. Mothers who reported having high parenting self efficacy reported having more partner emotional support ( $b = 0.38, p < 0.00$ ), and more other family member emotional support ( $b = 0.24, p < 0.01$ ) than mothers who reported having lower parenting self-efficacy.

### **Ethnicity Interactions**

To understand how ethnicity moderates the relationship between the support predictors and their outcomes, I examined interactions between ethnicity and the significant support predictors. I conducted additional individual regression analyses with the support predictors that proved significant from the previous set of regressions. In these regression analyses, I included the following: the six demographic control variables: mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism, the significant support predictor, and the ethnicity interaction (i.e., LatinoXSupportPredictor).

For family quality of life, of the four significant support predictors, the interaction between partner emotional support and Latino had a non-significant trend ( $b = 0.34, p = 0.08$ ). As it is more difficult to get significance for interactions in regression models, I used a more relaxed p-value to determine whether to include it in my final model ( $p > 0.10$ ). This variable was added to the final regression model. Posthoc comparisons of this interaction reveal that partner emotional support has a greater influence on family quality of life for Latina mothers than for non-Latina mothers (see Figure 3).

For satisfaction with life, of the four significant support predictors, none of the interactions with those predictors proved significant.



Table 8: *Standardized Coefficients for Individual Regressions*

	Family Quality of Life	Satisfaction with Life	Parenting Self- Efficacy
Partner Non Child-Centered Instrumental Support	0.19**	0.19*	-0.02 (ns)
Partner Child-Centered Instrumental Support	0.14†	0.03†	-0.03 (ns)
Other Family Member Non Child-Centered Instrumental Support	0.17*	0.11 (ns)	0.02 (ns)
Partner Emotional Support	0.41***	0.37***	0.38***
Other Family Member Emotional Support	0.39***	0.30***	0.24**

*Note.* The above numbers are standardized beta coefficients. Five separate regression analyses were conducted with each support-related predictor and the demographic control variables: Ethnicity, mother's education, mother's employment status, child's age, child's gender, child's functioning level, and child's disability diagnosis (autism or other intellectual disability).

†p < 0.10 \*p < 0.05 \*\*p < 0.01 \*\*\*p < 0.001

Figure 3: Graph of Interaction Term: Ethnicity and Partner Emotional Support (LatinoXPESupport) for Family Quality of Life

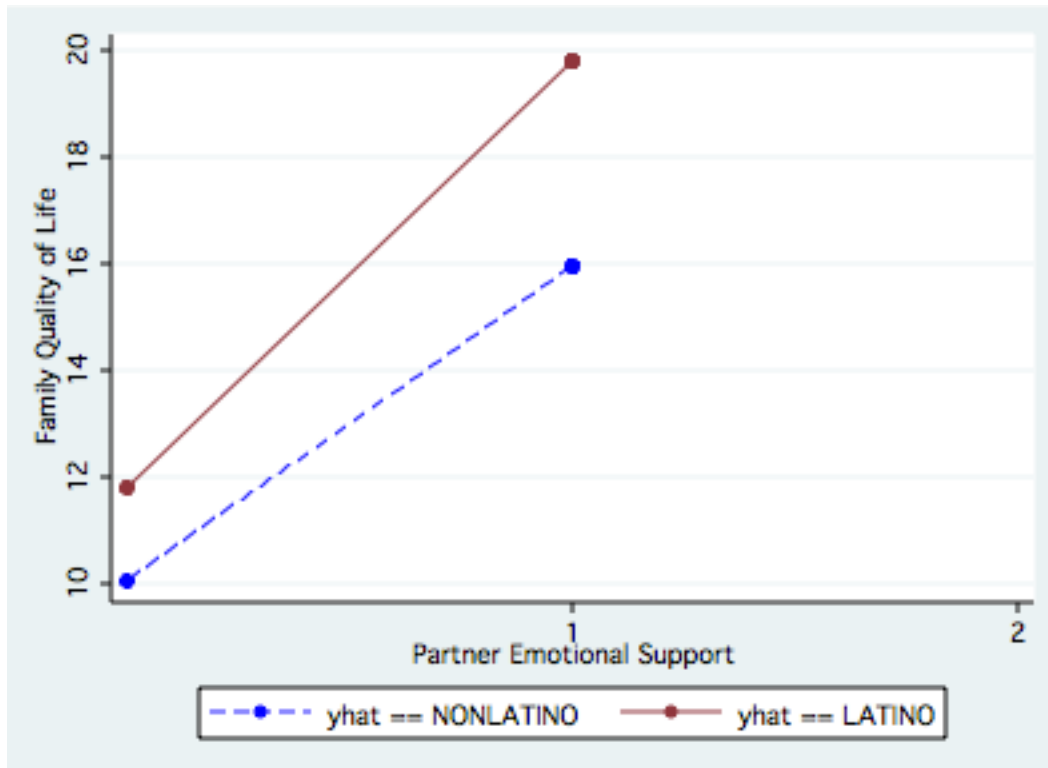


Figure 3. The two regression lines above are not parallel. The line for Latinos has a steeper slope than the line for non-Latinos. The effect of partner emotional support differs based on the mother's ethnic status. Partner emotional support has a greater influence on family quality of life for Latina than for non-Latina mothers.

For parenting self-efficacy, of the two significant support predictors, the interaction between ethnicity and partner emotional support (LatinoXPESupport) significantly predicted parenting self-efficacy ( $t = 0.53, p < 0.01$ ). Posthoc comparisons of the interaction reveal that partner emotional support has a greater influence on parenting self-efficacy for Latina mothers than for non-Latina mothers (see Figure 4).

### **Multivariate Regression Models Using Support Predictors**

To understand the combination of support predictors that best predict each outcome, I conducted one regression analysis for each outcome variable that included all six demographic control variables and all six support predictors.

Family quality of life was regressed on partner child-centered instrumental support, partner non child-centered instrumental support, partner emotional support, other family member child centered instrumental support, other family member non child-centered instrumental support, other family member emotional support, the interaction between ethnicity and partner emotional support (LatinoXPESupport), and the demographic control variables: mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism (see Table 9). Mothers who reported having a high family quality of life reported having more other family member non child-centered instrumental support ( $b = 0.16, p < 0.05$ ), more partner emotional support ( $b = 0.23, p < 0.05$ ), and more other family member emotional support ( $b = 0.33, p < 0.00$ ) than mothers who reported having a low family quality of life. The interaction between ethnicity and partner emotional support illustrated a non-significant trend. Partner emotional support had a greater influence on parenting self-efficacy for Latina mothers than for non-Latina mothers ( $t = 0.24, p < 0.17$ ). The entire model was significant ( $p < 0.00$ ) and the variance explained by this model was 41%.

Satisfaction with life was regressed on partner child-centered instrumental support, partner non child-centered instrumental support, partner emotional support, other family member child centered instrumental support, other family member non child-centered instrumental support, other family member emotional support, and the demographic control variables: mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism (See Table 10). Mothers who reported having a high satisfaction with life reported having more partner emotional support ( $b = 0.31, p < 0.00$ ), and more other family member emotional support ( $b = 0.26, p < 0.001$ ) than mothers who reported having a lower satisfaction with life. Each of the support predictors independently significantly predicted family quality of life when controlling for the six demographic variables and the other support predictors. The entire model was significant ( $p < 0.00$ ) and the variance explained by this model was 26%.

Parenting self-efficacy was regressed on partner child-centered instrumental support, partner non child-centered instrumental support, partner emotional support, other family member child centered instrumental support, other family member non child-centered instrumental

support, other family member emotional support, the interaction between ethnicity and partner emotional support (LatinoXPESupport), and the demographic control variables: mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism (See Table 11).

Mothers who reported having high parenting self-efficacy reported having more other family member emotional support ( $b = 0.19, p < 0.01$ ). The interaction between ethnicity and partner emotional support also significantly predicted parenting self-efficacy ( $b = 0.55, p < 0.01$ ). Partner emotional support had a greater influence on parenting self-efficacy for Latina mothers than for non-Latina mothers. The entire model was significant ( $p < 0.00$ ) and the variance explained by this model was 31%.

Figure 4: Graph of Interaction Term: Ethnicity and Partner Emotional Support (LatinoXPESupport) for Parenting Self-Efficacy

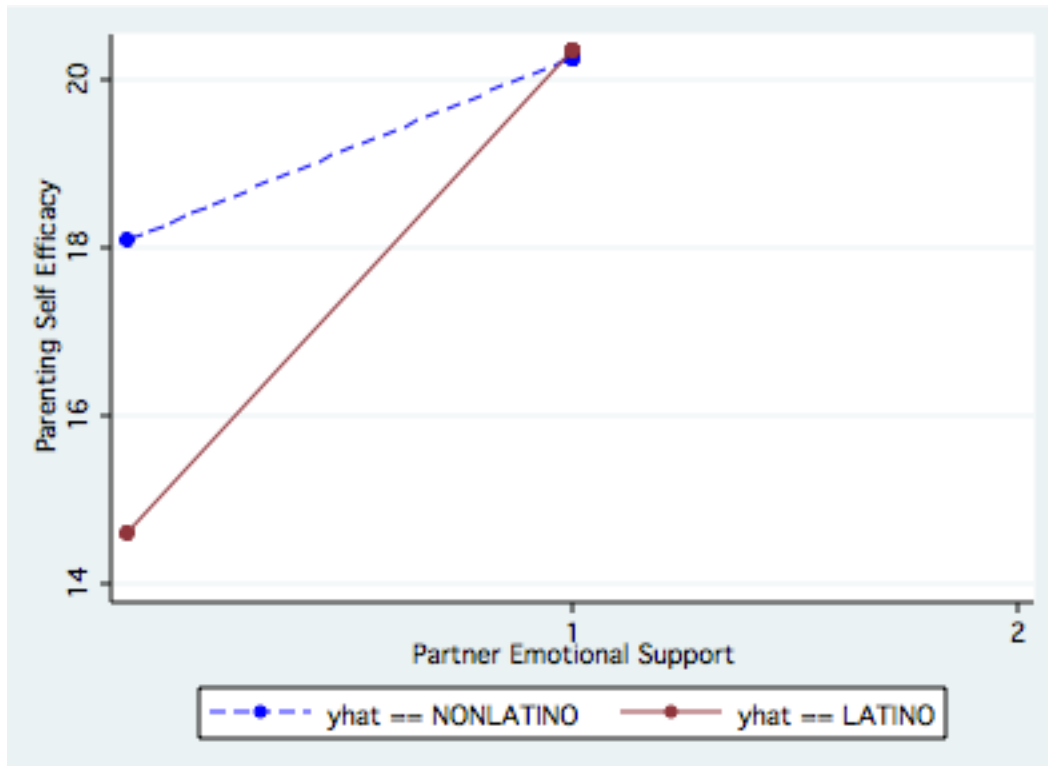


Figure 4: The two regression lines above are not parallel. The line for Latina mothers has a steeper slope than the line for non-Latina mothers. The effect of partner emotional support differs based on the mother's ethnic status. Partner emotional support has a greater influence on parenting self-efficacy for Latina than for non-Latina mothers.

Table 9: Final Regression for Research Question Two: Family Quality of Life

	Family Quality of Life			
	$\beta$	Robust Standard Error	Standardized $\beta$	95% CI
Mother's ethnicity	-0.67	2.51	-0.04 (ns)	-5.64 - 4.30
Mother's education	-2.56	1.26	-0.17*	-5.06 - -0.06
Child's Age	-0.12	0.23	-0.04 (ns)	-0.57 - 0.34
Child functioning	2.82	1.06	0.18**	0.72 - 4.92
Autism	-0.73	1.25	-0.05 (ns)	-3.19 - 1.74
Child's gender	0.11	0.98	0.01 (ns)	-1.82 - 2.04
PCCISupport	-0.08	0.27	-0.02 (ns)	-0.61 - 0.45
PNCCISupport	0.29	0.24	0.08 (ns)	-0.20 - 0.77
OFCCISupport	-0.02	0.25	-0.01 (ns)	-0.51 - 0.47
OFNCCISupport	0.60	0.25	0.16*	0.10 - 1.09
PESupport	4.18	2.08	0.23*	0.07 - 8.29
OFESupport	5.17	1.11	0.33***	2.98 - 7.37
LatinoXPESupport	3.45	2.68	0.24(ns)	-1.86 - 8.76
Adjusted R <sup>2</sup>			0.41	
F			8.23***	

Note. OFNCCISupport = Other family member non child-centered instrumental support; PEsupport = Partner emotional support; OFESupport = Other family member emotional support.

n = 138.00

†p ≤ 0.10 \*p ≤ 0.05 \*\*p ≤ 0.01 \*\*\*p ≤ 0.001

Table 10: *Final Regression for Research Question Two: Satisfaction with Life*

Satisfaction with Life				
	$\beta$	Robust Standard Error	Standardized $\beta$	95% CI
Mother's ethnicity	1.22	0.46	0.24**	0.30 - 2.14
Mother's Education	-0.14	0.44	-0.03 (ns)	-1.01 - 0.74
Child's age	0.02	0.09	0.02 (ns)	-0.15 - 0.19
Child functioning level	0.59	0.41	0.12†	-0.21 - 1.40
Autism	-0.61	0.46	-0.12†	-1.51 - 0.30
Child's gender	-0.14	0.39	-0.03 (ns)	-0.91 - 0.64
PCCISupport	0.05	0.09	0.04 (ns)	-1.14 - 0.24
PNCCISupport	0.09	0.11	0.08 (ns)	-0.13 - 0.20
OFCCISupport	0.02	0.09	0.03 (ns)	-0.15 - 0.20
OFNCCISupport	0.11	0.11	0.09 (ns)	-0.11 - 0.33
PESupport	1.86	0.45	0.31***	0.96 - 2.75
OFESupport	1.34	0.41	0.26***	0.53 - 2.14
Adjusted R <sup>2</sup>		0.26		
F		5.05***		

*Note.* PESSupport = Partner emotional support; OFESupport = Other family member emotional support.  
n = 138.00

†p ≤ 0.10 \*p ≤ 0.05 \*\*p ≤ 0.01 \*\*\*p ≤ 0.001

Table 11: *Final Regression for Research Question Two: Parenting Self-Efficacy*

Parenting Self-Efficacy				
	$\beta$	Robust Standard Error	Standardized $\beta$	95% CI
Mother's ethnicity	-3.85	1.94	-0.33†	-7.70 - -0.01
Mother's education	1.41	1.03	0.12 (ns)	-0.64 - 3.44
Child age	0.53	0.18	0.21**	0.17 - 0.89
Child gender	1.38	0.96	0.11 (ns)	-0.52 - 3.27
Child functioning level	2.02	0.84	0.17*	0.36 - 3.68
Autism	-0.71	0.96	-0.06 (ns)	-2.61 - 1.19
PCCISupport	-0.17	0.21	-0.06 (ns)	-0.59 - 2.50
PNCCISupport	-0.29	0.19	-0.11 (ns)	-0.67 - 0.09
OFCCISupport	0.26	0.19	0.12 (ns)	-0.12 - 0.63
OFNCCISupport	-0.16	0.22	-0.06 (ns)	-0.59 - 0.28
PESupport	0.98	1.48	0.07 (ns)	-1.95 - 3.92
OFESupport	2.31	0.97	0.19**	0.39 - 4.23
LatinoXPESupport	6.45	2.17	0.55**	2.16 - 10.74
R <sup>2</sup>		0.31		
F		6.65***		

*Note.* PESupport = Partner emotional support; OFESupport = Other family member emotional support.

n = 138

†p ≤ 0.10 \*p ≤ 0.05 \*\*p ≤ 0.01 \*\*\*p ≤ 0.001



### **Research Question Three: Examination of the Relation Between Familism and the Three Outcome Variables and the Moderator Effect of Familism**

#### **Descriptive Statistics of Familism**

Mothers' scores on the attitudinal familism scale differed significantly. T-test results show that these differences are statistically significant ( $t = 4.19, p < 0.001$ ) (see Table 12). Furthermore, the differences in the mean familism score between Latina mothers and non-Latina mothers, revealed a large difference in the standard deviation: 0.76. Latina mothers report significantly higher familism scores than non-Latina mothers.

#### **Understanding the Moderator Effect of Familism**

In addition to examining descriptive statistics, another purpose of this study was to understand the moderating effect of familism on the relation between the support indicator variables and each outcome variable. I conducted a two-step data analysis process. First, to understand the relation between familism and the outcome variable, I added the familism variable into an OLS regression model which included the demographic control variables: mother's education, mother's ethnicity, child's gender, child's level of functioning, and whether the child has autism, the significant support predictors from the analysis in research question two, and any significant interaction terms from the analysis in research question two. Second, to understand how familism moderates the relationship between the significant support predictors and the outcome variable, I created interaction variables between familism and the significant support predictors, and added them to a second OLS regression.

In the first regression analyses, the same support predictors from the analysis in research question two were still significant in each model, and familism did not significantly predict family quality of life, satisfaction with life, or parenting self-efficacy.

In the second regression analyses, the familism variable and the interaction terms pertaining to the significant support predictors from the previous model were entered into the regression model for each outcome variable. The interaction terms and the familism variable proved significant in the family quality of life model only (See Table 13). Specifically, mothers who reported having a high family quality of life reported having a higher sense of familism ( $b = 0.52, p < 0.01$ ). Also, partner emotional support alone did not predict family quality of life, but its interactions did. Specifically, partner emotional support was moderated by ethnicity and familism ( $b = 0.47, p < 0.01, b = -0.50, p < 0.01$ ).

Posthoc comparisons of the interactions revealed that ethnicity and familism beliefs had significant effects on partner emotional support. Specifically, the interaction between familism and partner emotional support showed that a strong belief in familism is more important for mothers with no partner emotional support than for mothers with some or a lot of partner emotional support ( $b = -0.50, p < 0.01$ ) (see Figure 5). According to this analysis, when mothers

displayed a high sense of familism and a high sense of partner emotional support (e.g., there is a match between actual familism and expectations of partner emotional support); they had a higher family quality of life than mothers who had a low sense of familism but high partner emotional support (e.g., there was a mismatch between actual familism and expectations of partner emotional support). The entire model was significant ( $p < 0.00$ ) and the variance explained by this model was 50%.

Table 12: *Descriptive Statistics Familism Variable*

	N	M	SD
Latina	85	2.81	0.20
Non-Latina	62	2.62	0.31

*Note.* T-test showed Latina mothers had significantly higher levels of familism than non-Latina mothers.

\* $p < 0.05$  \*\* $p < 0.01$  \*\*\* $p < 0.001$

Table 13: *Final Regression for Research Question Three: Family Quality of Life*

	Family Quality of Life			
	$\beta$	Robust Standard Error	Standardized $\beta$	95% CI
Mother's ethnicity	-3.60	2.67	-0.24 (ns)	-8.89 - 1.69
Mother's education	-1.83	1.30	-0.12 (ns)	-4.41 - 0.75
Child age	-0.13	0.23	-0.04(ns)	-0.59 - 0.32
Child gender	-0.14	0.97	0.01 (ns)	-1.78 - 2.06
Child functioning	3.51	1.05	0.23***	1.43 - 5.60
Autism	-0.27	1.15	-0.01 (ns)	-2.55 - 2.01
OFNCCISupport	0.59	0.19	0.16**	0.19 - 0.98
PESupport	1.11	2.54	0.06 (ns)	-3.92 - 6.14
OFESupport	5.32	1.09	0.34***	3.16 - 7.48
Familism	14.14	4.63	0.52**	4.98 - 23.31
LatinoXPESupport	7.14	2.85	0.47**	1.51 - 12.78
FamilismXPESupport	-15.06	4.83	-0.50**	-24.61 - -5.50
FamilismXOFNCCISupport	-1.11	0.63	-0.09 (ns)	-2.37 - -0.14
Adjusted R <sup>2</sup>			0.50	
F			9.66***	

*Note.* OFNCCISupport = Other family member non child-centered instrumental support; PESupport = Partner emotional support; OFESupport = Other family member emotional support.

n = 138

†p ≤ 0.10 \*p<0.05 \*\*p<0.01 \*\*\*p<0.001

Figure 5: *Graph of Interaction Term: Familism and Partner Emotional Support for Family Quality of Life*

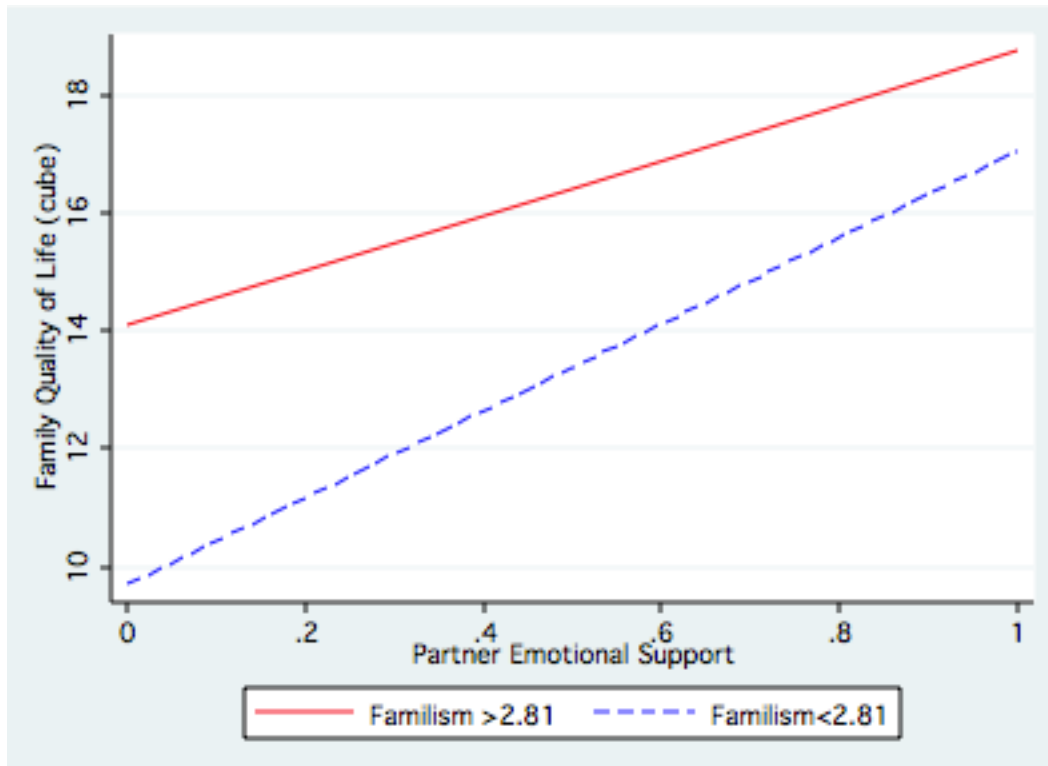


Figure 5. Median score on familism (2.81) was used to differentiate between mothers who perceive having a high level of familism with those who perceive having a low level of familism.

In this figure, the regression lines are not parallel. Each of the values on the line representing mothers who have a higher sense of familism is greater than each of the values on the line representing mothers who have a lower sense of familism. The coefficient for the interaction term is -0.50 which represents the difference in the slope between mothers who have a high familism score and mothers who have a low familism score. As partner emotional support increases, family quality of life increases at a higher rate for mothers with a lower sense of familism than for mothers with a higher sense of familism. When mothers display a high sense of familism and a high sense of partner emotional support (e.g., there is a match between actual familism and expectations of partner emotional support); they have a higher family quality of life than mothers who have a low sense of familism but high partner emotional support (e.g., there is a mismatch between actual familism and expectations of partner emotional support).

## CHAPTER FOUR

### Discussion

To date, the literature shows that mothers who care for a child with a cognitive disability experience more stress and depression than mothers who care for typically developing children or children with less severe disabilities. Latina mothers in particular, face a greater likelihood of depression and stress than non-Latina mothers caring for a child with an intellectual disability, due to a lack of social and community resources available to the mother; Latina mothers have poorer health and are more likely to be in poverty than non-Latina mothers (Magaña, et al., 2004). But also, research shows that even after controlling for these demographic characteristics, caring for a child with an intellectual disability is particularly stressful for Latina mothers, above and beyond the effects of poverty (Blacher et al., 1997). These differences may be attributed to certain cultural factors that may be prevalent in certain Latino communities. For example, mothers who endorse attitudinal familism are expected to prioritize their family relationships, thus neglecting their own emotional and psychological needs which may lead to more stress and depression.

Although these cultural factors may be useful in understanding why Latina mothers experience more stress and carry a greater caregiving burden than non-Latina mothers, they may also be useful in understanding how Latina mothers understand and capitalize upon particular types and sources of support to ameliorate their negative psychological outcomes. Although the current research identifies support as a protective factor against stress and depression for non-Latina mothers, little research exists that examines *how* support mitigates the negative psychological outcomes for Latina mothers who care for children with intellectual disabilities (Bailey, et al., 1999; Canary, 2008).

This study was designed to examine how support alleviates the negative psychological outcomes for Latina mothers who care for a child with an intellectual disability by examining specific types and sources of support that may be related to the cultural notions described above. First, as familism is an important concept for some Latino families, I chose to focus on the specific types and sources of familial support available to Latina mothers as compared to non-Latina mothers who care for a child with an intellectual disability. The types of support are exemplified by emotional as compared to instrumental support and child-centered as compared to non child-centered support. The sources of support are exemplified by the supporter (i.e., partner support as compared to other family member support). Second, as some Latino families adhere to particular cultural notions of gender (i.e., machismo), I chose to identify the sources of support as partner focused versus other family member focused.

More specifically, the goals of the study were: (1) to identify specific types and sources of support that are useful to Latina and non-Latina mothers; (2) to examine the relation between familial support and family well-being within a culturally diverse sample of mothers caring for a child with intellectual disabilities; and (3) to understand whether culturally situated beliefs (i.e.,

familism) moderate the relationship between a mother's perceived support and her family and caregiver well-being.

Findings indicate differences between Latina and non-Latina mothers with respect to certain demographic characteristics. For example, Latina mothers were primarily unemployed immigrants, who spoke Spanish in the home, had, at most a high school education, and had a family income of between \$25,000 and \$35,000 per year. The non-Latina mothers were primarily employed non-immigrants who spoke English in the home, were at least high school educated, and had a household income of over \$50,000 per year.

There were also differences with respect to familism and perceived emotional support. Latina mothers reported less partner emotional support than non-Latina mothers. There were no significant differences between Latina and non-Latina mothers with regards to perceived instrumental support. Also, Latina mothers reported a stronger endorsement of familism than non-Latina mothers.

With respect to the second research question, I found significant relations between perceptions regarding certain types and sources of support and women's individual psychological and family well-being controlling for mother's education level, mother's ethnicity, child's gender, child's age, child's functioning level, and whether the child had autism. Mothers who reported more partner and "other family member" emotional support reported having a higher family quality of life, better life satisfaction, and improved parenting self-efficacy, as compared to mothers who reported having less partner or "other family member" emotional support. Also, mothers who reported having more "other family member" non child-centered instrumental support reported having a higher family quality of life as compared to mothers who reported less of this type of support.

With respect to the third research question I found that familism significantly moderated the relation between familial support and family well-being for certain outcome variables. Mothers who adhered to the notion of familism, and reported high levels of partner emotional support reported a higher family quality of life than mothers who adhered less to the notion of familism but reported high levels of partner emotional support.

In the following sections, I will discuss and interpret more specific findings of the current study and implications for research and practice. In addition, I will also discuss the limitations of the study, and recommendations for future research.

Research question one examined the difference between Latina and non-Latina mothers with regards to six specific types and sources of support. Latina and non-Latina mothers were similar on five of the six indicator variables that were assessed (two emotional support variables and four instrumental support variables). Mothers showed significant differences in their perceived amount of partner emotional support only. Latina mothers reported having less partner emotional support than non-Latina mothers. Overall, in spite of the structural differences

between Latina and non-Latina mothers, these mothers did not differ on five of the six support indicator variables.

Certain culturally-situated beliefs involving gender roles may explain the fact that Latina mothers reported having less partner emotional support than non-Latina mothers. For example, Latino families live in a patriarchal social context, and may adhere to certain cultural norms regarding gender differences; differentiated roles that exist between mothers and fathers (Magaña, et al., 2004). Mothers are expected to care for the children and maintain the household, whereas fathers are expected to financially support the family (Bassuk, Perloff, & Garcia Coll, 1998). Recent studies have found distinct cultural concepts specific to Latino families, pertaining to these types of gender differences. Cauce and Domenech-Rodriguez (2002) explain that “values that have been considered distinctly Latino include... *machismo*...[and] *marianismo*...” (Cauce & Domenech-Rodriguez, 2002, p.12). *Machismo* is the belief that males should comply with stereotypical male gender roles (e.g., provide financial support to the family) (Cauce & Domenech-Rodriguez, 2002). Consequently, the provision of emotional support may not be considered a stereotypical “male” characteristic. Thus, Latino men may not believe it is their role to provide emotional support to their partner. *Marianismo* is based on the ideal woman, the Virgin Mary, and emphasizes the woman’s role as mother and her willingness to sacrifice her own needs for her own children (Cauce & Domenech-Rodriguez, 2002). Consequently, Latina mothers may not expect emotional support from their partner, they may in fact believe that they alone must care for the children and maintain the household, as that is their role. Therefore, the expectation of support from any source (e.g., partners and family members) may not be relevant given certain culturally-situated beliefs and expectations about gender roles.

Structural factors may also explain why Latina mothers reported having less partner emotional support than non-Latina mothers and why there are no differences between Latina and non-Latina mothers with regards to instrumental support. For example, due to the high cost of living in California, a caregiver’s partner may be required to hold more than one job in order to adequately provide for his family and may not be available to provide emotional support to the caregiver. In fact, according to the Migration Policy Institute, in 2006 Mexican immigrant men were more likely to participate in the civilian labor force in the U.S. as compared to Mexican immigrant women (Terrazas, 2010). This was also evident in the current sample. As the chi-square analyses illustrate, there were significant differences between Latina and non-Latina mothers with respect to their employment status ( $X^2 = 27.46, p < 0.00$ ). Latina mothers were primarily unemployed and non-Latina mothers were primarily employed. Furthermore, of the 146 mothers sampled in the study, most of their partners (140) were working either full or part-time outside of the home. Thus, for either structural or cultural reasons, Latino partners (i.e., fathers) are more likely to be in the workforce than Latina mothers and unable to offer emotional support.

Other structural factors may also explain why there are no differences in partner instrumental support between the two groups. As one third of the instrumental support activities described in the Daily Accommodations Measure, rely on supporters/individuals engaging in the



community (e.g., going grocery shopping, attending parent-teacher conferences, or taking the child to a doctor's appointment), these Latina mothers may not have the resources necessary to complete these activities without support. For example, of the current sample of 84 Latina mothers, 92% are immigrants; these mothers may not have access to adequate transportation (e.g., a driver's license), or may not be proficient in English. In fact, according to the Migration Policy Institute, about three quarters of the Mexican immigrant population in the U.S. were limited in their English language proficiency (Terrazas, 2010). Therefore, these mothers may have to rely on the partner (i.e., the father), who may have more access to these resources as he works outside of the home (e.g., he may have learned English on the job and may hold a driver's license in order to get to his job), to drive them to the grocery store, or to communicate with the child's doctor. These structural factors may help explain why Latina mothers report no differences from non-Latina mothers in their levels of partner instrumental support.

Furthermore, due to the structural circumstances of the current sample of Latina mothers (e.g., low socio-economic status, immigrant, and not English proficient), their cultural notions of gender roles and expectations may have shifted. Certain instrumental activities involving community engagement (e.g., communicating with teachers and service providers), that the mother may have been able to complete without support if she were in her home country, she may be unable to accomplish here for a variety of reasons (e.g., lack of English proficiency). Thus, she may now expect her partner to engage in these activities and to incorporate them into his role and obligations as a parent, thus, adapting her cultural notions of gender roles and expectations. Now she may expect her partner to financially provide for his family *and* be responsible for communicating with service providers and doctors. The fact that Latina mothers may have adapted their cultural definitions of male gender roles may explain the fact that there are no differences between Latina and non Latina mothers in their levels of partner instrumental support.

Research question two examined the relation between the six support indicator variables and family and caregiver well-being. Within this section, three categories of findings are discussed. The findings from (a) the demographic control variables: mother's education level, mother's ethnicity, child's gender, child's age, child's functioning level, and whether the child has autism; (b) the significant support predictors; and (c) the ethnicity interaction variables.

For the findings related to the mother's demographic characteristics, only family quality of life showed a significant relation with mother's education level. Specifically, more educated mothers reported having a lower family quality of life. This finding can be interpreted in a couple ways. First, a more educated mother, who may understand the details of her child's condition better than a less educated mother, may feel helpless and unable to have a positive family quality of life. Second, the more educated mother may expect a higher family quality of life, but when her expectations are not met, she may be more disappointed in her family quality of life than a less educated mother who did not have such a high expectation for her family quality of life. The greater the gap between a mother's expectations and her reality, the greater the disappointment (or the lower her quality of life).

The child characteristics led to more abundant findings, specifically related to the severity of the child's disability. For example, mothers who reported that their child plays well with others reported a higher family quality of life, a higher life satisfaction, and a high sense of parenting self-efficacy than mothers who reported that their child does not play well with others. In a related finding, mothers who reported having a child with autism reported having a lower individual life satisfaction than mothers who reported having a child with a different intellectual disability. Thus, when a mother feels confident about her child's abilities, particularly in socializing with other children, she has an improved sense of well-being. This may be attributable to the fact that when a mother feels that her child is "less disabled" that child exhibits less of a burden, or less stress on the mother's and the family's well-being. Current research examining the relation between mothers' levels of stress and child characteristics, exhibit similar findings; child behavior problems, particularly pertaining to social behavior, are related to a mother's higher level of stress and depression (Beckman, 1983, Floyd & Gallagher, 1997; Holroyd & McArthur, 1976). For example, Beckman (1983), found that specific child characteristics (e.g., social responsiveness, temperament, and repetitive behavior) increase the mother's level of stress in caring for that child (Beckman, 1983). Therefore, a mother experiences more stress when caring for a child who exhibits more severe behaviors and characteristics related to his or her disability.

Other attributes related to the characteristics of the child also proved significant. Specifically, mothers who reported having an older child and a male child reported having a higher sense of parenting self-efficacy than mothers who reported having a younger child and a female child. These findings may also be attributable to the mother's sense of burden or stress in caring for a particular type of child. For example, older children may exhibit more independence and may be better able to care for themselves rather than relying on their mother. Older research suggests that caregivers experience more stress when caring for older children with disabilities and boys as compared to girls (Farber & Kirk, 1959). However, more recent research has found that the age and sex of the children were not related to the amount of stress reported by mothers (Beckman, 1983). Thus, the contradictory findings indicating that age and sex of the child relate to caregiver well-being suggest a need for further research in this area.

Although understanding the relation between certain demographic characteristics and caregiver and family well-being is useful, I was primarily interested in understanding how the six support predictors relate to family and caregiver well-being, as these traits can be ameliorated if necessary, and may explain certain cultural factors (e.g., familism) related to support. Emotional support and other family member non child-centered instrumental support were significantly related to family (i.e., family quality of life) and caregiver (i.e., individual life satisfaction and parenting self-efficacy) well-being. More specifically, other family member non child-centered instrumental support, partner emotional support, and other family member emotional support significantly predicted family quality of life. Partner emotional support and other family member emotional support significantly predicted individual life satisfaction and parenting self-efficacy.

These findings suggest that emotional support may be more important than instrumental support for caregivers to feel satisfied with their life and efficacious about their parenting. This preference towards emotional support is understandable because it is a more appropriate type of support to address psychological well-being. Instrumental support does not address a caregiver's feelings as a parent. It is more useful for managing the day to day activities of the household. Emotional support -- the perception of reassurance and nurturance from family members -- seems more relevant to the psychological well-being of the caregiver. Current research also supports the hypothesis that the presence of emotional support is associated with caregiver well-being (George & Gwyther, 1986; Marcenko & Meyers, 1991; Miller, Townsend, Carpenter, Montgomery, Stull, & Young, 2001). For example, Miller and colleagues examined findings from four community-based caregiving studies. The samples were caregivers who cared for children and adults with health problems (e.g., Alzheimers). They found that only one type of social support was consistently related to caregiver distress. Specifically, less emotional support was associated with higher levels of distress among caregivers in two of the four community studies (Miller, et al., 2001).

Other family member non child-centered instrumental support, on the other hand, does relate to family quality of life, along with partner and other family member emotional support. If a caregiver has more support from family members to complete daily household tasks (e.g., washing dishes, doing laundry, cooking dinner) she may have more time to focus her efforts on child related activities (e.g., finding effective interventions for her child, or helping her child complete homework). Furthermore, this combination of instrumental and emotional support that significantly relate to family quality of life show that family quality of life is an indicator of broad family well-being and calls for a variety of types of support including emotional and instrumental support to address its multidimensional characteristics. These three support predictors represent a variety of types and sources of support that may be useful for mothers to call upon in sharing the various tasks that come with running a smooth household and effectively meeting the needs of each child.

There is limited research specifically addressing how instrumental support relates to caregiver and family well-being for families who care for a child with an intellectual disability. Most of this research defines social support more broadly, incorporating emotional, instrumental, and informational support into one construct: social support. However, some current research examining how older individuals are supported in their later life, describes a relation between instrumental support and well-being (Marcenko & Meyers, 1991; Silverstein, & Bengston, 1994). Silverstein and Bengston (1994), examined whether intergenerational instrumental support is related to the emotional distress for 328 White middle class elderly grandparents. They found that instrumental support from adult children was particularly detrimental to this sample as it was perceived as intrusive and a threat to the grandparent's autonomy. Although these findings contradict the findings of the current study, the samples are vastly different. It seems reasonable to assume that instrumental support from adult children may infringe upon the elderly parent's autonomy. However, if family members provide instrumental support to a mother who cares for a child with a disability, that mother may welcome the support in order to alleviate her caregiving

burden and the stress of caring for her child with disabilities. Furthermore, this mother may be more distressed, thus she may elicit more instrumental support than an aging grandparent.

Although non child-centered instrumental support was significantly correlated with family quality of life, child-centered instrumental support was not. There may be a few reasons for this result. First, mothers are more likely to see the results of non child-centered instrumental support because it consists of concrete activities (e.g., grocery shopping, washing dishes, and cleaning the house). Child-centered instrumental support involves abstract activities (e.g., helping the child with homework, or engaging in parent-teacher conferences). Thus, mothers may not see the results of the child-centered instrumental support. For example, if there is food in the refrigerator, and dinner is made, the mother sees immediate and tangible results from the non child-centered instrumental support. Whereas if a family member takes her child with a disability to a speech therapist, she may not see an immediate result from this support. Second, non child centered instrumental support benefits the whole family. For example, if another family member makes dinner one night, or goes grocery shopping for the week, every member of the family will likely benefit from that task. However, if a family member plays with the child, or helps the child complete his or her homework, only the child (and perhaps the mother) will benefit from that type of support. Considering that non child-centered support was only correlated with family quality of life, an outcome pertaining to the well-being of the entire family, it is reasonable to assume that in order for mothers to have a high quality of life, they would expect support that would benefit the entire family.

The third set of findings from research question two examine how ethnicity moderates the relation between familial support and well-being. Of the three outcomes variables, the ethnicity interaction, proved significant for parenting self-efficacy only. In other words, partner emotional support had a greater influence on parenting self-efficacy for Latina mothers than for non-Latina mothers.

Latina mothers may be more likely to adhere to the notion of machismo, the belief that males should comply with stereotypical male gender roles (e.g., provide financial support to the family) (Cauce & Domenech-Rodriguez, 2002), and thus may, on the whole, expect less partner support than do non-Latina mothers. Those who receive emotional support from their partner may be then deeply affected by it. In comparison, non-Latina mothers may be more likely to expect partner emotional support and, because they take this support more for granted, it is less likely to affect their self-efficacy. Furthermore, the Latina mothers in this sample may be more dependent on partner emotional support because they feel more alienated and uncertain in their social and community environment. Most of the Latina mothers are primarily immigrant (92%), come from a lower socio-economic status (73% of the Latina mothers in this sample have an average household income under \$50,000), and have less education (66% of these Latina mothers have only earned a high school degree or less), as compared to non-Latina mothers who are primarily non-immigrants (76%), have an average household income of over \$100,000 (i.e., 50% of the non-Latina sample), and have more education (92% of the non-Latina mothers have attended college, have a bachelor's degree, or have a graduate degree). For the Latina mothers

who reported having partner emotional support, those partners may realize the alienation and loneliness that the mothers feel and attempt to provide them with emotional support to compensate for the lack of social or community resources to ensure that they feel efficacious.

Current literature suggests that it is difficult for Latino families who care for a child with an intellectual disability to access services because they do not trust, and have poor communication with service providers (Heller, et al., 1994; Bailey, et. al., 1999; Larson, 1998; Shapiro, et. al., 2004). If Latina mothers have a higher sense of parenting self-efficacy, they will feel more empowered to access services and more likely to trust and communicate with with service providers. When Latina mothers perceive that they have partner emotional support, their parenting self-efficacy improves. Thus, in order to build trust and improve communication between Latina mothers and service providers, Latina mothers must be provided with effective partner emotional support to build a strong family unit that can meet the challenges that may arise when accessing formal services. Partner emotional support buffers the negative effects of mistrust and communication as experienced by Latina mothers and results in greater parenting self-efficacy.

Research question three examined how familism moderates the relation between the six support predictors and the three outcome variables. First, I found that Latina mothers have a significantly greater sense of familism than non-Latina mothers. Also, familism significantly predicted family quality of life, but not individual life satisfaction or parenting self-efficacy. Lastly, the interaction between familism and the various support predictors illustrated significance with only partner emotional support. Mothers who display a a low sense of familism but high partner emotional support have a lower family quality of life than mothers who display a high sense of familism and a high sense of partner emotional support.

The first finding, Latina mothers have a significantly greater sense of familism than non-Latina mothers, illustrates the presence of certain cultural factors related to support among this sample. Latina mothers have a stronger sense of familism - the belief in the commitment of family members to their family relationships (Steidel & Contreras, 2003) - than non-Latina mothers. Familism emphasizes the importance of family closeness, family obligation to its members, and family members equally contributing to the well-being of the entire family (Cauce & Domenech-Rodriguez, 2002). As Steidel & Contreras (2003) describe, one component of attitudinal familism involves the belief in familial support in times of need. This finding therefore shows that certain cultural factors (i.e., a belief in familism) may contribute to Latina mothers' expectations of support. In others words, mothers who hold a strong belief in familism may expect more familial support than mothers who do not hold such a strong belief.

The second finding, mothers who believe in familism have a higher family quality of life than mothers who do not believe in familism, illustrates that certain cultural factors such as familism may be important predictors of family well-being. Mothers who believe in familism have a strong commitment to their family members, have a strong family identity, and are physically and emotionally bonded to their family (Steidel & Contreras, 2003). As is evident

with this finding, mothers who adhere to this multidimensional notion of familism have a higher family quality of life due, in part, to the perceptions of family support and unity that this concept embodies. If a mother has a strong sense of familism, she believes that her family is emotionally and physically bonded to her and available to support her, which may lead to a higher family quality of life.

The third finding, mothers who display a low sense of familism but high partner emotional support, have a lower family quality of life than mothers who display a high sense of familism and a high sense of partner emotional support, can be understood in two key ways. First, mothers who may not hold strong familism beliefs, but have at least some actual partner emotional support, have a relatively high family quality of life as compared to those who do not strongly believe in familism, and experience little actual partner emotional support. Second, mothers who perceive that they have partner emotional support, have a higher family quality of life. But for those mothers who perceive little partner emotional support, the presence of a strong belief in familism can buffer the effects of low partner emotional support, also resulting in a high family quality of life.

This finding can be interpreted using three different theoretical perspectives. First, early research in the field of psychology concludes that when there is a match between an individual's expectations and an individual's reality, the individual will be more satisfied than when there is a mismatch between the individual's expectations and the individual's reality (Everson, et al., 1984). In my study, caregivers who reported a match between their expectations of partner emotional support and their levels of familism, reported a higher family quality of life than those caregivers who reported a mismatch between their expectations of partner emotional support and their levels of familism (e.g., caregivers who report low expectations of support but engage in higher familistic behaviors). Mothers who reported high perceptions of partner emotional support but a low sense of familism had a lower family quality of life than mothers who reported high expectations of partner emotional support and high levels of familism. This finding supports the theory that a person's reality and their expectations or perceptions of reality must match in order to optimize one's outcomes.

Second, recent psychological research found that families who have a strong commitment to nonconventional family values can protect children against certain environmental risks and promote positive academic outcomes (Weisner, & Garnier, 1992). Weisner and colleagues followed 146 families who adhered to non-conventional family lifestyles (e.g., unorthodox family organization, abnormal family values, or an unusual commitment to their family lifestyle) over a 12 year period. They found that children with the best academic outcomes came from families who held a strong commitment to meaningful family values (even unconventional values), while those children doing less well came from families who had a lower commitment to these values (Weisner & Garnier, 1992). Furthermore, Weisner and colleagues believed that broader family outcomes (e.g., parenting self-efficacy and family well-being), may also be positively related to this strong commitment to family values (Weisner & Garnier, 1992). Similarly, in the current study, mothers who held a strong commitment to familism, even with

low partner emotional support, had a high family quality of life as compared to mothers who held a weak commitment to familism and low partner emotional support, had a lower family quality of life.

Third, and possibly most important, is the unique contribution of this finding to the stress and coping psychological perspective; more specifically, the relation between support and stress for families with children with disabilities. In this field, social support contributes to families' health and well-being by protecting caregivers from the adverse effects of stress. In other words, support is used as a buffer to alleviate certain stresses associated with caring for a child with a disability. This conclusion came from previous research, that relied on examining how traditional forms of support (e.g., service provider support) alleviate stress for families who care for a child with a disability. However traditional forms of support (i.e., partner emotional support) may not be as important to culturally diverse families as culturally-defined notions of support (i.e., familism). According to this finding, mothers who perceived little partner emotional support, but held a strong belief in familism, still reported a high family quality of life. Therefore, familism, a multidimensional cultural concept, partly defined by the amount and quality of family support that an individual receives, may be more useful as a measure of support for caregivers who adhere to this cultural concept than traditional notions of support (i.e., partner emotional support). Defining support more broadly, based on the unique cultural beliefs of some families, may help to more effectively buffer the effects of stress on culturally diverse families who care for a child with an intellectual disability.

## **Limitations**

The following discussion examines the limitations of the current study pertaining to the sample and the measures.

## **Sample**

There were several limitations pertaining to the sample characteristics and recruitment. First, the relatively low response rate<sup>3</sup> to the recruitment of sample participants may have resulted in a biased sample. Second, the sample was a self-selected group of Latina and non-Latina mothers who were already connected to the service system. In order to further assess the significance of familial support, a future sample would contain two groups; one group of mothers who were connected to the service system, and one group of mothers who were not connected to the service system. In this way, researchers could compare how familial support relates to family and caregiver well-being in both groups and whether familial support compensates for a lack of service provider support. Third, the sample consisted of only mothers who care for children with intellectual disabilities. In order to examine broader, more multidimensional outcomes (i.e., family quality of life), the sample should consist of additional family members who live in the household (e.g., fathers, siblings, grandparents) and who provide care for the child with the

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<sup>3</sup> The non-profit corporation yielded a 23.00% response rate and the teaching hospital yielded a 35.00% response rate.

intellectual disability. The other family caregivers may have different perspectives about the types and sources of support that they find useful and that may be correlated to certain family outcomes.

Fourth, the current sample is a diverse Latino sample; these families come from a variety of countries in central and south America. In order to have a more nuanced understanding of the types and sources of support that are useful to certain Latino families, it is important to examine these questions within similar groups (e.g., only Mexican caregivers who care for a child with a cognitive disability). Finally, in the current sample, the Latina mothers were of significantly lower socioeconomic status than the non-Latina mothers, thus all the comparisons regarding cultural notions of gender roles and family are confounded with socioeconomic status and mother's education level. In order to examine whether certain culturally situated beliefs are related to familial support and explain caregiver well-being, above and beyond demographic factors (e.g., socioeconomic status), it is important to recruit a Latina and non-Latina sample that is similar across these demographic characteristics.

### **Support Indicator Variables**

Although the support indicator variables were quite detailed and specific in identifying the type and sources of support available to caregivers, there were certain limitations to these measures that must be addressed. First, as we were limited in the types of questions that could be asked in a brief telephone survey, we were unable to get a comprehensive understanding of the participants' perceived emotional and instrumental support. The current indicator variables, particularly the child-centered instrumental support, and the non child-centered instrumental support variables, examine the quantity of support available to the caregiver rather than the quality of support. The emotional support variables broadly assess the quality of the support (e.g., whether the family member listens to the mother if she needs to talk about her concerns regarding her child). Further research would benefit from support indicator variables that assess the quality and quantity of the available instrumental and emotional support. Also, these support indicator variables were created and developed by the researcher rather than created by the caregivers. As Coyne and colleagues (1990) discuss, future research in this area could focus on participant led interviews that allow the caregiver to identify the types and sources of support that he or she finds useful (Coyne, Ellard, Smith, 1990).

### **Implications**

In order for service providers to be effective, they must engage with families in a collaborative, culturally valued fashion. They must engage in a self-reflective, dialogic process involving identifying both their own cultural norms and those of the families with whom they work (Kalyanpur & Harry, 1999). Based on the findings from this study, there are certain ways in which service providers can work more effectively with Latina mothers who care for children with disabilities. First, this study shows that partner emotional support, other family member emotional support, and other family member non child-centered instrumental support provide



caregivers with the confidence that they are effective parents and their families have a greater quality of life. Thus, practitioners can adapt their services based on this new knowledge. For example, if practitioners capitalize upon the specific supports that are most useful, readily available, and lead to positive caregiver and family outcomes, such as partner emotional support, these caregivers may be more motivated, efficacious, and willing to learn about and carry out child interventions, which may lead to better child (and family) outcomes. On the other hand, if these predictive supports (e.g., partner, other family member emotional support, and other family member non child-centered instrumental support) are not available to caregivers, practitioners may support caregivers in finding similar familial supports that may be useful to the caregiver. Practitioners should also rely on the importance of familism for caregivers by encouraging other family members to participate in certain services that embody familism (e.g., incorporating family members in home based interventions, or including family members in the child's IEP meetings).

Furthermore, mothers must be empowered to address their own health and psychology within the context of the cultural values that they adhere to. For example, service providers may acknowledge that the mother is committed to caring for her child and family (e.g., she embodies the cultural notion of *marianismo*), while also helping her understand that she can fulfill this commitment more effectively by improving her well-being. Consequently, culturally competent services should go beyond addressing language issues and enable Latina mothers to shift their cultural notions of gender and family to capitalize upon the support that may be available to them in their own communities. By empowering Latina mothers to make connections within their communities (e.g., actively seek out Spanish speaking support groups for mothers who care for a child with an intellectual disability), they may feel more efficacious, and better able to navigate the service system. Recent research has identified that the potential number of social ties increases as caregivers are more linked to their communities (Keefe & Padilla, 1987). And the amount and quality of the social ties may be correlated to a mother's well-being (Kawachi & Berkman, 2000). Thus, mothers must be connected to their communities in order to have positive outcomes.

## **Future Research**

Future research should be focused in four areas. First, more quantitative studies should be conducted with nationally representative samples. Second, we must engage in qualitative research (e.g., open-ended interviews, or observations, assessing the specific supports that each family finds useful), to emically understand cultural definitions and expectations of emotional and instrumental support that are useful for Latina and non Latina mothers who care for a child with an intellectual disability (Coyne, et al., 1990). Third, researchers should examine how other caregivers within the family perceive support. The goal is to investigate how each family member can support and be supported by the family to improve family well-being. Fourth, we must move beyond explaining caregiver well-being with the typical demographic characteristics (e.g., poverty, low education level), as these factors do not fully explain caregiver well-being (Blacher, et. al., 1997). Future research must focus on how cultural notions of family and gender

roles may explain the relation between support and well-being for mothers who care for a child with an intellectual disability. In fact, a recent study by Magaña and colleagues (2004) calls for more research to examine how environmental challenges (e.g., poverty) interact with certain cultural factors to affect family well-being (Magaña, et al., 2004). My study begins to examine these moderator relationships by exploring how certain environmental supports (e.g., partner emotional support) interact with certain cultural norms (i.e., familism).

The current study makes two key contributions to the current literature on Latino families and their children with disabilities. First, the sample size is moderate. The majority of the studies examining Latino families and their children with disabilities are qualitative with small sample sizes, limiting the generalizability across larger samples. This study had a larger sample size, allowing for the findings to be generalizable to a larger group. Second, this study challenges global notions of support by first identifying types and sources of support more specifically, and second, by identifying certain cultural concepts of family as alternative and effective support for Latino families and their children with disabilities. In sum, this study begins to identify the importance of familial support, and define support more broadly based on the unique cultural beliefs of families and their children with intellectual disabilities.

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