A MULTICULTURAL EXAMINATION OF THE RELATIONSHIP
BETWEEN COPING AND WELL-BEING IN PARENTS
OF CHILDREN WITH DISABILITIES

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A dissertation submitted in partial fulfillment of
the requirements for the degree of
DOCTOR OF PHILOSOPHY

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To the Faculty of Washington State University:

The members of the Committee appointed to examine the dissertation
of ERIN KIKU OKUMOTO find it satisfactory and recommend that it be accepted.

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Abstract

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Prior coping literature has typically focused on Western models, with an emphasis on changing one’s environment or situation from an individualistic perspective. However, alongside the increasing cultural diversity in the U.S., there has been a recent movement towards examining collectivistic models of coping in reaction to the exclusion of cultural orientations that consider one’s impact on relationships in managing stress. People of Color who have children with disabilities are a highly vulnerable group given their barriers to services and experienced stigma from outside and within their cultural communities. Using the Double ABCX Model (McCubbin & Patterson, 1983) as a framework, this study explored the relationship between caregiver stress and well-being outcomes, while testing the mediating effects of coping. The sample consisted of 386 caregivers of children with disabilities. The majority of the sample were female (96%). Participants completed self-report questionnaires to assess for family strains, stigma, coping, and well-being. Structural equation modeling (SEM) was employed to determine the effects of Individualistic and Collectivistic coping strategies on well-being for both European
Americans and People of Color. Engagement, Disengagement, and Collectivistic Coping strategies significantly predicted overall Well-Being. Coping was a partial mediator for many of the relationships between Pile-up factors and Well-Being. People of Color endorsed Collectivistic Coping strategies to a greater degree than European Americans. Results from this study demonstrate the use of bi-cultural coping amongst Caregivers of Color and highlight the utility and importance of considering coping and well-being from a cultural lens in working with this population at large.
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Dedication

This dissertation is dedicated to my parents, Michael and May Okumoto. Thank you for your unwavering support.
CHAPTER ONE
INTRODUCTION

The prevalence of children with disabilities is rising, affecting about 2.8 million of school-aged children (5-17 years) in the United States in 2010 (U.S. Census Bureau, 2011). Under the Individuals with Disabilities Education Improvement Act (IDEA), infants and school-aged children who are deemed at risk for developmental disabilities are eligible for free and appropriate educational services (U.S. Department of Education, 2004). While there are many definitions of disability, the IDEA (2004) defines disability as persons:

(i) with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this title as ‘emotional disturbance’), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (ii) who, by reason thereof, needs special education and related services (Sec. 602).

Children who are served under federal supported special educational services, as sanctioned by the IDEA, has risen from 8.3 to 13.8 percent between 1976 to 2005 due to the rising prevalence of children identified with specific learning disabilities in the late 20th century and other health impairments and autism in the early 21st century (National Center for Education Statistics [NCES], 2013). In addition to the IDEA, the movement towards deinstitutionalization and the Americans with Disabilities Act has contributed to increased visibility of this population (Reichman, Corman, & Noonan, 2008). Furthermore, neonatal technology (e.g. DNA testing) to determine the risks or presence of such developmental delays before birth contribute to increased diagnoses of these conditions.
Statement of the Problem

Caregiving for a Child with a Disability

Caregiving for a child with a disability (CWD) can impact the nuclear and extended family with both positive and negative effects (Reichman et al., 2008). Studying the impacts that caregiving has on the family is important because such effects may in turn impact the child. Studies have shown that the familial environment (e.g. emotional environment, parent-child relations, and family cohesiveness) can influence CWD’s socio-emotional functioning (Floyd & Zmich, 1991; Mink, Blacher, & Nihira, 1988). Negative impacts may include demands on caregivers’ physical and mental/emotional resources. Coordinating and advocating for child services (e.g. health care, therapy, educational services, and child care) require increased time, financial resources, and adjustment in the caregiver’s lifestyle and occupational path. Such stress may also have negative implications on a caregiver’s emotional, mental, physical, and social health. Caregivers may also assume blame and responsibility for their child’s disability, which may influence their self-efficacy and esteem as a parent. These effects combined may then put strain on familial relationships as well. Finally, parents of CWD may assume caregiving responsibilities for an extended period of time, with worries about the child’s future after their death (Reichman et al., 2008).

Among these many considerations, there are many individual predictors that affect a caregiver’s perceived stress or impact in having a CWD. In a study that examined caregivers’ impact of having a child with an Autism Spectrum Disorder (ASD), they found that repetitive behaviors, poorer behavioral functioning, and lower parent social support contributed to greater perceived impact of having their child (Bishop, Richler, Cain, & Lord, 2007). In addition,
Blacher and McIntyre (2006) demonstrated that their child’s behavioral problems almost entirely accounted for the relationship between their child’s Intellectual Disability (ID) diagnosis and maternal well-being, depression, and stress (Blacher & McIntyre, 2006). On the other hand, IQ, severity of social deficits, larger households, and diagnoses did not significantly predict perceived impact (Bishop et al., 2007).

**Culture and Disability/Mental Health Services**

Within the families that warrant scholarly attention and public services, People of Color (including, but not limited to African Americans, Asian Americans, Latina/o Americans, Native Americans, and Pacific Islanders) who have children with disabilities in the U.S. are an important population to consider, given the additive oppressions they encounter in their social communities as a “double minority” (disability status within an ethnic minority group; Chan, 1981). In other words, they may experience social isolation from the experiences of racism as a Person of Color within the disability community and ableism as a person associated with disability within their respective cultural communities (Borum, 2007; Zane & Yeh, 2002).

Stigma towards those with mental or emotional disabilities has been demonstrated amongst People of Color, especially for Asians/Asian Americans (Saetermoe, Scattone, & Kim, 2001; Scior, Addai-Davis, Kenyon, & Sheridan, 2013).

Due to the increased complexity in service utilization as a double minority, significant disparities exist in mental health conditions and care across racial groups in the U.S. For example, there is a disproportionate amount of African Americans in public special education diagnosed with mental retardation and emotional disturbance (Zionts, Zionts, Harrison, & Bellinger, 2003). Additionally, African Americans are found to experience higher prevalence
rates of chronic mental illness and disability, which may relate to lower socio-economic status compared to other racial populations in the U.S. (Alston & Turner, 1994; Kessler et al., 1994). Native Americans are a vulnerable population as well, as they experience greater psychological distress than the average U.S. population due to the historical trauma that they have endured, encompassing generational oppression and cultural loss (Brave Heart, 1998). A within racial group comparison also revealed that Asian American and Pacific Islanders with disabilities experience more discrimination, distress, and poorer mental health than those without disabilities (Zane & Yeh, 2002).

Despite an increased need for services, People of Color still experience greater unmet mental health needs. Reasons for this disparity include language barriers, lack of resources, low socioeconomic status, inaccessibility or cultural insensitivity of services, and negative perceptions towards mental health care or help seeking in general (Choi & Wynne, 2000; Dote-Kwan, Chen, & Hughes, 2009; Matthews, Corrigan, Smith, & Frances, 2006). African American and Latino children in particular, were found to encounter higher health care barriers, including poorer quality of care, in comparison to European American counterparts (Magaña, Lopez, Aguinaga, & Morton, 2013; Magaña, Parish, Rose, Timberlake, & Swaine, 2012). Urban African American parents with children in the special education system noted low income, financial burden, and lack of instrumental resources (transportation, health care, resources) as barriers to receiving adequate care for their children (Zionts et al., 2003). For Latinos, lack of information, culturally insensitive or inadequate service quality, poor resources (instrumental and financial), and language barriers are amongst the difficulties they face in gaining access to early intervention services (Dote-Kwan et al., 2009; Magaña et al., 2012). In addition, Latino parents
who had developmental disabilities reported dissatisfaction with professionals not providing enough information or time with them regarding their child’s condition, with their child’s diagnosis of ASD being received almost a year later than European American children (Magaña et al., 2012; Magaña et al., 2013). Additionally, multicultural parents of CWD indicated that language issues were one of the strongest barriers that they encountered, as it impeded their mutual understanding of needs and relationship with service providers (McCallion, Janicki, & Grant-Griffin, 1997).

People of Color have also been found to underutilize mental health services at lower rates than the general U.S. population for a number of cultural reasons. Aside from tangible factors that contribute to barriers to care, cultural beliefs of the cause of the child’s disability and related societal shame may determine their tendency to seek resources and willingness to disclose about their child’s disability to social networks or the community (Buser, 2009; McCallion et al., 1997). Many studies note that People of Color are reluctant to seek services or were dissatisfied with Western medical or mental health services because of their lack of sensitivity, consideration for, or understanding of their cultural views or practices to the issues at hand (Dote-Kwan et al., 2009; Goodkind, Gorman, Meredith Hess, Parker, & Hough, 2015; Magaña et al., 2012; McCallion et al., 1997; Zionts et al., 2003).

Perceptions of stigma and need to hide their CWD appears to affect caregivers’ willingness to seek community services (McCallion et al., 1997). Cultural reactions and attributions to disability-related stigma range between and within cultures (McCallion et al., 1997). In Westbrook and Legge’s (1993) comparative ethnic study in Australia, collectivistic communities (Chinese, Greek, Italian, and Arabic) were shown to endorse a stronger perception
that having a son with a disability was a tragedy, and found a greater desire to conceal the
disability of their child. Furthermore, Greek and Chinese communities deemed having a CWD to
be more shameful than other ethnic groups in this study. These findings may suggest that
collectivistic cultures may hold more stigmatization towards people with disabilities than
individualistic cultures. Acknowledging that the experiences and perceptions of stigma vary
greatly within People of Color, many caregivers of such groups indicate that their experience of
stigma results in their desire to conceal their child’s disability due to anticipated negative effects
of disclosure (McCallion et al., 1997; Kunitz, 1983; Zhou, 2000). For Asian Americans, there is
also a cultural value in “saving face” or preserving the reputation of oneself in the community, as
well as the pressure to live up to the model minority myth that society places upon them, which
encompasses stereotypes that Asian Americans are hard-working and successful in their
academic and occupational careers (Mereish, 2012). Cultural attributions to the cause of the
child’s disability may elicit reactions of self-blame and shame in Asian families of CWD (Cho,
Singer, & Brenner, 2000; Daudji et al., 2011; Ryan & Smith, 1989; Sadao, 2000; Westbrook &
Legge, 1993). Similarly, there was shame and embarrassment associated with mental illness and
its treatment for African Americans who perceived that seeking professional help was an
indication of weakness and inability to manage their hardships (Lindsey et al., 2006).

The ideology of People of Color towards what mental illness is attributed to can also
influence their endorsement of Western mental health services. For example, compared to
European Americans who more likely endorsed biological or environmental factors, African
Americans were more likely to attribute mental illness to God’s will (Schnittker, Freese, &
Powell, 2000). Participants in this group who endorsed religious attributions to mental illness
were less likely to use mental health services (Schnittker et al., 2000). In addition, medication
was also not endorsed in African Americans to treat mental illness for a number of reasons
including mistrust, weakness, and fears of dependency (Matthews et al., 2006; Ward, Clark, &
Keidrich, 2009). For Native Americans and other indigenous communities, preferences towards
the services they seek may be highly related to not only the stigma of mental illness in their own
culture, but also a difference in their ideology about health and illness from a spiritual and
communal standpoint, which conflicts with Western individualistic medical practices (Goodkind
et al., 2015). Many indigenous and Eastern philosophies also approach well-being from a holistic
perspective, rather than separating the mind, body, and spirit (Torsch & Xueqin Ma, 2000).

Another way in which the Native Americans perceive disability and mental illness
differently than Western medical practice is that wherein Western medicine focuses on the
individual’s cause of his/her psychopathology, Native Americans see it as illness in the entire
community, as connected to flaws within socio-economic and political frameworks (Goodkind et
al., 2015). In addition, African Americans may demonstrate a mistrust or skepticism towards the
mental health community because of historical and present day racism that they experience
through this system, including the Tuskegee study and other unethical research studies,
overrepresentation of psychotic and mental retardation diagnoses in their racial group, and
microaggressions (Constantine, 2007; Freimuth, Quinn, Thomas, et al., 2001; Snowden, 2003).
For such reasons, some African American families were resistant to accepting testing or services
for their children, with the perception that it would unfairly label and limit their child’s
opportunities (Matthews et al., 2006). In addition, Native American youth of the Diné (Navajo)
community who utilized mental health services indicated that they felt misjudged and labeled in
their services, and felt that this system was just a way to control and punish them (Goodkind et al., 2015).

In addition, People of Color may be naturally tend to use culturally influenced or appropriate coping methods outside of the scope of professional mental health services. Rather than seeking professional help, People of Color may seek help or support rather from general physicians, nuclear and extended family members, and religion (Lindsey et al., 2006; Snowden, 1998; Taylor, Chatters, & Levin, 2004). They may also have coping style with preferences towards either enduring the problem with self-sufficiency and will power and/or keeping the problem to themselves as to not burden others or show weakness (Chang, 2015; Snowden, 2001; Yeh & Wang, 2000). Communities with indigenous spiritual or holistic approaches to health may rely on remedies that can restore balance and harmony through many dimensions, including natural remedies and spiritual healers (Diken, 2006; Goodkind et al., 2015; Maloni et al., 2010; Torsch & Xueqin Ma, 2000). Another commonly cited way that People of Color alternatively cope with having a CWD is through family and/or social support, emphasizing the roles of interdependent and collective care among parents, siblings, and for some, even extended family members (Cohen, Holloway, Dominguez-Pareto, & Kuppermann, 2014; Cohen, Holloway, Dominguez-Pareto, & Kuppermann, 2015; Ha, Greenberg, & Seltzer, 2011; McCallion et al., 1997; Zea, Quezada, & Belgrave, 1994). In these families of CWD from collectivistic cultures, families were found to operate and make decisions within culturally defined dynamics and hierarchical roles (McCallion et al., 1997).

Thus, it is clear that People of Color with CWD are a particularly vulnerable community in light of the multiple societal, economic, and cultural stressors as they affect their caregiving
experiences. However, the socio-cultural barriers and difficulties that People of Color with CWD face seem to be largely unrecognized and ill-addressed in research and practice. The evidence in the literature not only demonstrates the systemic and cultural barriers to the quality services, but also highlights the need for research to explore and examine cultural aspects of their experiences to increase collaboration and cultural sensitivity towards these communities.

**Strengths-Based Approach**

Amongst the existing literature, there is disagreement regarding the effects or outcomes of raising a CWD. While some studies focus on risk factors and negative outcomes of parent health in their failure to adjust to the demands of caretaking, others focus on the resiliency factors that support the positive adjustment or adaptation of parents or support the case that there are minimal differences between the well-being of parents with or without a CWD (Ha et al., 2011). On the one hand, Reichman et al. (2008) assert that studies often associate poorer mental health outcomes with parents and family members of CWD. For instance, Breslau and Davis (1986) found that while rates of Major Depressive Disorder were similar in parents of CWD and parents without CWD, greater depressive symptomatology existed in the former group (Breslau & Davis, 1986). Darbyshir and Kroese (2012) also found that parents of children with intellectual disabilities showed poorer psychological well-being than the general parent population. In addition to mental health outcomes, Seltzer, Greenberg, Floyd, Pettee, and Hong (2001) found that social activity is reduced in parents of CWD.

On the contrary, there is also a large body of research that demonstrates that the majority families are able to overcome and thrive through the experience of having a CWD (Baker, Blacher, & Olsson, 2005; Kersh, Hauser-Cram, & Warfield, 2006; Lewis et al., 2006; Olsson &
Hwang, 2008), and that the functioning of families with CWD are no different than those without (Mahoney, Sullivan, & Robinson, 1992). King et al. (2006) examined changes in belief systems of families with autism or Down syndrome, finding that parents were initially overwhelmed with the diagnosis, but increased their hope and sense of control by witnessing the resiliency of similar parents. Similarly, in a ten-year longitudinal study, Gray (2002, 2006) found that parents of children with autism cite much fewer coping strategies through time, possibly due to increased parenting self-efficacy in managing caregiving demands. Parents relied less on treatment services, family support, and religious practices. In general, parents transitioned from problem-focused to emotion-focused coping strategies by increasing their use of reframing the situation cognitively or finding spiritual meaning of their experience. This adjustment may be due to changes in resources (decline in respite programs after school age), becoming accustomed to the lifestyle of having a child with autism, or having more realistic expectations of their child’s limitations and prognosis. While the majority of participants in this study demonstrated resilience, the smaller portion of this group that remained at a high level of distress over time (i.e. maladjustment) were found to face unique stressors including severe child behavior problems and concern for the child’s violence and anxiety about the child’s future and one’s career.

Regardless of the debate over parent outcomes, there is value in recognizing and identifying resilience factors that impact parent adjustment. Examining mediating or moderating factors such as coping could help to explain the difference between resilient and maladaptive groups. The strengths-based approach (Saleebey, 1992) focuses on the positive attributes and resources of people that promote their resiliency in spite of their stressors and challenges. In
support, Olsson and Hwang (2008) found that protective factors explained significant variation in well-being outcomes.

Given the socio-cultural vulnerability of diverse families of disabilities and the lack of research to inform understanding and culturally relevant practice, focus in this area is demanded. Thus, to address the need to study parents of CWD from strengths-based and culturally sensitive perspective, this investigation will explore the development of coping research, caretaking of a CWD, and well-being. Each domain will examine these constructs from both western and cross-cultural perspectives.

**Limitations and Future Directions**

Taken together, coping in parents of CWD is an area of research that warrants further development. First, while qualitative studies shed light on the unique and subjective experiences of these parents, there is a dearth of quantitative studies to elucidate the statistical relationships between coping factors and well-being amongst this population. Second, there is a lack of existing research on People of Color in such research samples. Coping research in general primarily include White American participants (Bjorck, Cuthbertson, Thurman, & Lee, 2001; Dunahoo, Hobfoll, Moniier, Hulsizer, & Johnson, 1998; Yeh, Arora, & Wu, 2006), which questions the generalizability of applying formerly established coping theories to the greater U.S. population. Consideration of other populations and cultures is important because of the growing diversity of the U.S. demographic, with People of Color projected to consist more than half of the U.S. population by 2044 (U.S. Census Bureau, 2015). This population is particularly important to study in this area of interest because of the implications of marginalization placed on the intersection between two minority statuses (ethnic and disability), wherein cultural shame
can play a salient role. In applying Crenshaw’s (1999) theory of intersectionality, which acknowledges the interactions between multiple social and personal identities, the cumulative experiences of discrimination that families of disabilities may face across multiple identities (e.g., disability, socio-economic, race) are additive and intertwined, further posing risk onto one’s well-being.

Despite the need to consider various cultural populations in coping and mental health research, the majority of previous coping research has been framed in Western-driven, individualistic ideology and values such as autonomy and action-oriented problem solving from an intrapersonal lens. Although values such as interdependence and social harmony have been found to have salience on coping preferences for collectivistic cultures, they are often overlooked by the original coping models (Kuo, Roysircar, & Newby-Clark, 2006). Furthermore, coping studies commonly suggest a bias towards action-oriented coping styles which show correlations with positive adjustment outcomes, wherein avoidance and emotion-focused strategies that are more indirect forms of coping are associated with poorer mental health (Endler & Parker, 1990; Folkman, Lazarus, Gruen, & DeLongis, 1986, Lazarus & Folkman, 1984; Seiffge-Krenke, 1993). These results may arbitrarily place universal value on individualistic ideas of autonomy, while discounting culturally appropriate coping responses in other populations. In response, Yeh et al. (2006) developed a Collectivistic Coping model that considers alternative coping styles from Lazarus and Folkman’s (1984) model, including Family Support, Respect for Authority, Intracultural Coping, Relational Universality, Forbearance, Social Activity, and Fatalism.
Purpose and Hypotheses

In response to lack of cultural considerations in examining caregiving of CWD, this study will be a quantitative investigation of the relationship between caregiver stress, coping, and well-being of parents of CWD—both European Americans and People of Color. The purpose of this study is to examine the cultural nuances between People of Color and European Americans within a sample of parents of children with disabilities (CWDs) by examining collectivistic and individualistic coping patterns and their effect on well-being. While previous studies of this nature with this population have not been conducted, this study is an exploratory investigation. However, a tentative hypothesis can be made based on the Double ABCX Model (McCubbin & Patterson, 1983) in that caregiver stress will be related to well-being, with such relationship mediated by coping. In addition, cultural values, the experience of stigma, and the use of culturally-specific coping strategies may yield different outcomes depending on racial group identification.
CHAPTER TWO
LITERATURE REVIEW

The growing rates of children being diagnosed with disabilities in the U.S. creates increased awareness and needs for services for this population. Studies of families of CWDs display variable outcomes in terms of the parents’ adjustment to caregiving stressors, with some suggesting that they have lower mental health and well-being outcomes than parents without a CWD (Breslau & Davis, 1986; Darbyshir & Kroese, 2012; Reichman et al., 2008; Seltzer et al., 2001), and others suggesting that there is no difference, highlighting this group’s resilience (Baker, Blacher, & Olsson, 2005; Kersh, Hauser-Cram, & Warfield, 2006; Lewis et al., 2006; Mahoney, Sullivan, & Robinson, 1992; Olsson & Hwang, 2008). Because it is evident that some families adjust better than others in comparable situations, coping variables are often examined to explain the variability in outcomes.

Theoretical Model

From the preliminary work of Hill (1949), the Double ABCX Model (McCubbin & Patterson, 1983) was developed. This model explains how families adjust to stressful situations, with the premise that they have a natural tendency to maintain or restore stability through their dynamics and systems (McCubbin & McCubbin, 1996). The ABCX model thus, provides a framework that delineates the processes whereby family stressors (A) are mediated by coping, including the family’s resources (B) and appraisals of the stressor (C). Examples of family resources may be financial or social support. The appraisal of the stressor encompasses a holistic assessment of the perception of the severity and meaning of the stressor in consideration of the family’s ability to manage their stressors in light of their resources, abilities, and systems of
functioning (McCubbin, Dahl, Lester, Benson, & Robertson, 1976). During a family crisis however, a pile-up of stressors (AA) may overwhelm the family’s existing patterns of functioning or abilities to cope. The pile-up of stressors includes the family’s existing or more chronic stressors and the added stressors of the new crisis situation (e.g., the diagnosis of their child’s disability). Thus, this crisis elicits new coping resources (BB) and appraisals (CC) in order to adapt to the situation, such that these coping mechanisms mediate the relationship between family stressors and adaptation. The effectiveness of the coping processes influences whether or not the family is able to adapt (i.e., Bonadaptation) or not (i.e., Maladaptation). Bonadaptation indicates the family’s ease in adjusting to the crisis situation and the restoration of harmony, functioning, and well-being within the family (McCubbin & McCubbin, 1996). Using the McCubbin and Patterson’s (1983) ABCX model, different components of family resilience literature will be explored, including parental coping and well-being.

Coping

The Development of Coping Research

Since the early-mid 1900s, when Sigmund and Anna Freud popularized the idea of psychological defense mechanisms, the notion of coping has undergone extensive study and development (Somerfield & McCrae, 2000). Coping is commonly defined as the efforts to manage the demands of a stressor that are deemed to overwhelm one’s current resources (Folkman & Lazarus, 1991). The empirical measurement of stress and coping emerged during the cognitive movement in the 1960s-1970s, with research focusing on intrapsychic mediators between stress and dysfunction (Lazarus, 1993; Somerfield & McCrae, 2000). After the psychoanalytic movement lost its momentum, hierarchical trait theories derived, in which coping
was viewed as a person’s style or disposition in handling stress upon bi-dimensional categories (e.g. repression versus sensitization; Cohen, 1987). However, the process model subsequently gained prominence in the late 1970s. This theory views coping as an adaptation which changes over time and situation (Lazarus, 1993). Research on coping has since been an outstanding area of interest in contemporary psychology (Somerfield & McCrae, 2000).

**The Cognitive Theory of Stress and Coping**

The Cognitive Theory of Stress and Coping (Lazarus & Folkman, 1984) has been developed and revised by Lazarus and various colleagues over two decades (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). The theory consists of two processes including cognitive appraisal and coping. Cognitive appraisal is the evaluative process of determining if and how a stressor may affect one’s well-being. The first type of cognitive appraisal that one encounters is the *primary appraisal* in which the person deems whether or not the encountered event may be relevant to one’s well-being in the form of a likely harm, threat, or challenge. Usual emotions that result in these perceptions are fear and anger (Folkman & Lazarus, 1991). The meaning of the event, which may be transformed through the coping process, is considered the model’s most influential component on the outcomes (Kelso, French, & Fernandez, 2005). Following is the *secondary appraisal*, in which the individual gauges his or her coping resources and decides if and what can be done to attenuate the anticipated effects of the situation (Folkman et al., 1986).

After the individual decides what he/she can do to manage the situation (i.e. secondary appraisal), he/she implements coping strategies, which may include various forms of cognitive and behavioral efforts in attempts to manage the experienced stress (Lazarus & Folkman, 1984).
Coping is seen to influence the relationship between the environmental stressor and the emotional outcome—either by reducing the amount of negative emotion (i.e. moderator variable) or changing it to positive emotion (i.e. mediating variable; Folkman & Lazarus, 1988a; Lazarus, 1993). This model purports coping as a process, which suggest flexibility and change over time as the nature of the stressor unfolds (Folkman et al., 1986). This model also assumes the process to be contextual, meaning the individual’s response to the stressor is based on a comprehensive array of factors involving a person’s appraisals as well as resources (Folkman et al., 1986). Lastly, regardless of the effectiveness of reducing stress, this model suggests no prior assumptions of “good” or “bad” ways of coping (Folkman et al., 1986; Lazarus, 1993).

The two types of coping proposed by this model are problem-focused coping and emotion-focused coping. While problem-focused coping involves directly altering the person’s relationship with the environmental stressor, emotion-focused coping involves managing stressful emotions that result from the stressor (Lazarus, 1993). Studies show that both forms of coping were demonstrated in an overwhelming majority of college student (Folkman & Lazarus, 1985) and middle-aged adult samples (Folkman & Lazarus, 1980). Problem-focused coping was found to be more effective in cases that the person could change the situation, whereas emotion-focused coping proved more effective for situations that were more permanent, and thus, had to be accepted (Folkman, 2008; Lazarus, 1993).

Finally, the outcome follows the coping behavior which encompasses the resulting emotional reaction of the situation and evaluation of whether or not the stress has been resolved (Folkman et al., 1986; Kelso et al., 2005). Depending on this evaluation, a new perception (i.e. reappraisal) may ensue and influence the primary appraisal of a similar or repeated encounter.
Measurements

Coping research has resulted in a number of measures, which are divided into dispositional (i.e., trait) and episodic assessments (Cohen, 1991). Dispositional/trait measures assess one’s usual coping tendencies across a variety of stressors. Cohen (1991) asserted that because dispositional measures may draw from personality traits, they may be a useful way to demonstrate predictive validity in its connection to general health outcomes. Examples of such measures are the Byrne (1961) Repression-Sensitization Scale, the Coping-Avoidance Sentence Completion test (Andrew, 1970), the Defense Mechanism Inventory (Gleser and Ihilevich, 1969), and Joffe and Naditch’s (1977) Coping-Defense measure (Cohen, 1991). However, there has been substantial research to suggest that coping dispositions do not generalize to one’s actual coping behavior in stressful situations (Cohen, 1991), arguing against the use of these measures. Furthermore, previous literature supports the notion that coping methods vary for specific situations (Cohen, Kaplan, & Riggio, 1986) and that there is variation of coping methods even within dealing with a specific situation over time (Folkman & Lazarus, 1985). Episodic measures assess the coping mechanisms that are used in a specific situation (Cohen, 1991). Examples of episodic coping measures are Folkman and Lazarus’ (1988b) Ways of Coping Questionnaire, the Billings and Moos (1984) questionnaire, and the Cohen et al. (1986) assessment of coping modes. While these measures assess either dispositional or situational coping, the COPE questionnaire (Carver, Scheier, & Weintraub, 1989) was designed to have versatility in assessing both types of coping.

Although the WAYS is probably the most widely used, Cohen (1991) claims that there is
no determined “gold standard” assessment amongst scholars, being there is such large variability between each measures’ factors, methods, and purposes. Furthermore, it was stated that the choice in assessment should be based on the researcher’s purpose and the level of specificity and situation that is intended to be examined. New coping measures continue to be developed, with focus now on interpersonal and culturally specific methods of coping (Tweed & DeLongis, 2006).

Recent Developments in Coping Research

As the Cognitive Theory of Stress and Coping has been developed and revised numerous times since its beginnings in the 1960s, it continues to be refined by new empirical evidence (Folkman et al., 1986). Folkman (2008) has recently argued for the integration of positive emotions (e.g. happiness, relief, pride) in the model, as they have shown to occur as a result of appraising the initial event as a challenge (Folkman & Lazarus, 1985) and when a stressor is favorably resolved (Lazarus & Folkman, 1984). Furthermore, personality traits—traditionally thought to be stable dispositions, were also encouraged to be considered in examining individual tendencies toward certain coping styles, as they were recently shown to highly impact coping behaviors (Somerfield & McCrae, 2000).

Taken together, the application of coping research to theoretical development and informing practice continues to serve as a barrier to the progression of this area (Somerfield & McCrae, 2000; Ziegelmann & Lippke, 2009). Coyne and Racioppo (2000) suggested ways to bridge the discrepancy between research and practice, including setting a broader and more personalized set of outcome assessments to match the goals of the individual, and to assess for stress and coping behaviors in situation-specific ways. This method of narrowing situations and
individual needs will eventuate into targeted application of coping research and assessment within specific contexts. Somerfield and McCrae (2000) call for new designs including longitudinal repeated measures, high-context (i.e. situation specific) instruments, and multiple rater assessment. Nonetheless, the proponents to this field affirm the progression and hope for coping research by highlighting notable research studies that have answered the needs for longitudinal designs, microanalytic and in depth perspectives, and intra/inter-individual examination (Lazarus, 2000; Tennen, Affleck, Armeli, & Careney, 2000). Although Lazarus (2000) has argued for the advancement of research in this field, a commentary by Ziegelmann and Lippke (2009) still emanate similar sentiments as critics in the past—that there is still a call for the reconstruction of stress and coping research to translate into theory development (particularly a multi-dimensional model) and practice, with the suggestion of increased longitudinal studies that can be replicated experimentally to examine coping’s effect on change as opposed to descriptions of variation.

Another common criticism of coping research is previous samples include primarily European American participants (Bjorck, Cuthbertson, Thurman, & Lee, 2001; Dunahoo, Hobfoll, Monier, Hulsizer, & Johnson, 1998; Yeh et al., 2006), which questions whether Lazarus’ theory can be applied or generalized to other cultures. In addition, these studies commonly posit that action-oriented coping styles are correlated with positive adjustment outcomes, wherein avoidance and emotion-focused strategies that are more indirect forms of coping are associated with poorer mental health (Endler & Parker, 1990; Folkman et al., 1986, Lazarus & Folkman, 1984). Thus, the majority of previous coping research has been framed in
individualistic ideology and in values such as autonomy and action-oriented problem solving.

Yeh et al. (2006) explain that coping behaviors are largely influenced by one’s orientation towards collectivistic/interdependent or individualistic/independent self-construal. This identification is noted to influence one’s cognitions and affect (Markus & Kitayama, 1991), and is seen to be an important influence on one’s coping behaviors as well (Bailey & Dua, 1999; Cross, 1995; Lam & Zane, 2004). Self-construal may influence coping style by cultural reinforcement, wherein appropriateness or normalcy of certain coping behaviors is determined by its socio-cultural context (Lam & Zane, 2004; Lazarus & Folkman, 1984). Specifically, self-construals were purported to be a mediating factor between ethnicity and coping (Cross, 1995; Lam & Zane, 2004). Thus, those who endorse individualistic values may use more active forms of coping, which involves directly altering their environment or situation in order to effect change to meet their needs (Lam & Zane, 2004; Markus & Kitayama, 1991; Weisz, Rothbaum, & Blackburn, 1984). Conversely, collectivistic individuals may be motivated instead to maintain group cohesion and harmony, thereby leading them to focus on altering internal processes, rather than attending to the situation itself (Cross, 1995; Weisz et al., 1984). Thus, the problem lies wherein individualistic bias suggests action-oriented strategies as adaptive, and passively-oriented strategies as maladaptive or destructive, because the adaptability of these coping strategies are largely influenced by self-construal based on one’s culture. Furthermore, studies have shown that although behaviors have been acculturated to the dominant culture, values and norms (including coping patterns) are still consistent with the host country even amongst third and fourth generation Asian Americans (Hieshima & Shneider, 1994; Kim, Atkinson, & Yang,
Collectivistic Coping

In response to the lack of a theoretical model to account for a collectivistic model of coping, Yeh et al., (2006) devised a multidimensional theory based in extensive related research literature. Such dimensions were: Family Support, Respect for Authority, Intracultural Coping, Relational Universality, Forbearance, Social Activity, and Fatalism. Based in the Confucian principle of filial piety (Sue, 1994) and that collectivistic individuals belong to and rely more on fewer in-groups, family is a significant component of ego strength (Daly, Jennings, Beckett, & Leashore, 1995) and support. Collective identity was found to predict seeking help from family members amongst Japanese Americans (Yeh, Inose, Kobori, & Chang, 2001). On the other hand, sharing problems outside of the family is thought to bring shame on the family unit and is discouraged (Sue, 1994). Thus, reliance on one’s immediate family characterizes the dimension of Family Support. Respect for Authority involves seeking help from authority figures in the community, including parents and/or indigenous healers for guidance. Compared to individualistic cultures, Asian culture is more hierarchical in social structure, which may be influenced by Confucian tenants, which emphasizes respect for authority and filial piety.

Intracultural Coping involves rallying support from a network of an ethnic/cultural in-group member. Individuals may feel that their “individual” problem is seen more as a shared problem within the group, and would also want to keep the problem within the group as to not burden anyone else. Relational Universality involves getting support from others specifically involved in similar situations, in which comfort ensues from knowing others are dealing with relatable stressors. Forbearance is a coping strategy in which an individual withholds or conceals one’s
conflicting opinions or negative emotions related to a stressor in aims of promoting social 
harmony, while avoiding, or averting the importance of personal gain, interpersonal conflict, 
and/or embarrassing the other person (Ben-Ari & Lavee, 2004; Lee, 1997; McCarty et al., 1999).

Social Activity is used with social support from talking to others, as opposed to seeking 
professional help (Yeh et al., 2006; Yeh & Inose, 2002), which has been shown to be particularly 
beneficial in ethnic minorities compared to European Americans (Daly et al., 1995; Yeh et al., 
2006; Yeh & Inose, 2002). While individualistic societies often place positive emphasis on 
internal loci of control towards positive adjustment, collectivistic cultures find more flexibility 
between internal and external loci of control (Morling & Fiske, 1999), which implies Fatalism, or 
accepting outcomes of a situation as fate rather than trying to control or change it (Morling & 
Fiske, 1999).

In addition to Yeh et al.’s (2006) work, other collectivistic scales have been developed 
within the past decade, including: the Collectivistic Coping Style Measure (Moore & 
Constantine, 2005), the Collectivist Coping Styles Inventory (Heppner et al., 2006) the Cross-
Cultural Coping Scale (Kuo et al., 2006) and the Collective Coping Scale (Zhang & Long, 2006).

**Racial/Ethnic Variations in Coping**

Because of the recognized gap in literature regarding cultural considerations beyond that 
from a Western, individualistic lens from which early coping research derived, researchers have 
begun to address the need of understanding coping in diverse populations and cultural contexts. 
The existing multicultural research on coping consists largely of cross-cultural etic studies, 
which apply universal theories to all groups to find differences/similarities between them, with a 
smaller representation of emic studies, which seek to capture an individual culture’s ways of
coping as derived from its own indigenous perspective, values, and practices. This section will present a summary of the current existing literature on each major racial group in the U.S.

**Asian/Asian American Coping**

Asian/Asian American coping literature consists of many quantitative cross-cultural studies that tests hypotheses about their predicted indirect/passive ways of coping and differences in use of social support compared to the European American or general U.S. population. In addition, there are also a minority of studies that investigate Asian/Asian Americans coping from an indigenous perspective using a qualitative approach to capture and explain inherent differences in coping based in Eastern philosophies.

**Active/engaged versus passive/disengaged coping.** Cross-cultural coping studies often compare Asian or Asian Americans to European Americans on various coping constructs. At a broad level, researchers group coping strategies into two categories—active/engaged and passive/disengaged coping. Tobin, Holroyd, Reynolds, and Wigal (1989) define Engagement coping as actively attending to the stressor by directly seeking solutions to the problem or using social support. On the other hand, they define Disengagement coping as coping mechanisms that help to avoid the problem or situation that is causing distress (e.g. withdrawal, self-criticism). In general, research supports that Asian/Asian Americans display more internal and passive/disengaged forms of coping and less active or externally focused forms of coping than European American counterparts (Bjorck et al., 2001; Chang, 1996; Chang, 2001; Kim, Sherman, Ko, & Taylor, 2006; Lam & Zane, 2004; Sheu & Seldlcek, 2004; Taylor, Sherman, et al., 2004; Tobin et al., 1989; Tweed, White, & Lehman, 2004; Wong, Kim, & Tran, 2010), in
which there is less reliance on social support (Kim, Sherman, & Taylor, 2008) and more on problem avoidance and social withdrawal (Chang, 2001).

Wong, Kim, and Tran (2010) explain that culture shapes the ways that individuals appraise their stressors and coping resources (Lazarus & Folkman, 1984; Tweed & Conway, 2006). Most scholars point to the difference in values and subsequent coping motivation to differentiate the tendencies towards these coping styles. Particularly, Asian values such as preserving social harmony, avoiding negative reactions of others, accepting problems, and “saving face” by limiting disclosure seem to be relevant values that contribute to more internal or avoidant forms of coping (Inman & Yeh, 2007; Morling, Kitayama, & Miyamoto, 2002; Tweed & Conway, 2006; Tweed et al., 2004; Yeh et al., 2006). In addition, Tweed et al. (2004) add that high power distance or hierarchically structured cultural societies may emphasize acceptance of situations more than trying to change the situation, as to preserve this social structure.

Asian philosophical concepts may influence the Asian/Asian Americans’ preference towards internal coping as well. Eastern philosophies in general demonstrate the acceptance of suffering, which they believe involves both pleasure and dysphoria (Palsane & Lam, 1996). Thus, whereas Western philosophies focus on negative aspects of stress and adaptation and how to overcome it, tolerance of pain and suffering is normalized in Eastern philosophies. For instance, Buddhist philosophies view suffering as a necessary existence in life that derives from desires. The only way to transcend this suffering is to take the middle path between asceticism and indulgence. Similarly, with the Chinese concept of yin (light—aggression, overindulgence) and yang (dark—withdrawal, depression), these forces must be in harmony to reduce stress and prevent illness (Palsane and Lam, 1996). Furthermore, Taoism emphasizes the concept of wu
wei, in which ultimate state of being, which is in harmony the ebb and flow of the universe, accomplished by action without action or the ability to be adaptable.

While the literature supporting the notion that Asian Americans use more passive forms of coping compared to European American counterparts, there are a few studies that provide contradicting evidence or add to the complexity of the conclusions of former studies. For instance, Chang (1996) showed that as consistent with other studies, Asian Americans reported more use of disengaged coping mechanisms such as problem avoidance and social withdrawal than European Americans. However, no significant differences were found between Asian Americans and European Americans in engaged coping mechanisms such as problem-solving, cognitive restructuring expressing emotions, seeking social support, self-criticizing, and wishful thinking. Thus, although Asian Americans use more disengagement strategies than European Americans, they were just as engaged in their problem and emotion focused efforts as European Americans.

Cook and Hayes (2010) offered further opposing evidence compared to prior studies. They examined the difference between two types of internal coping, including control-focus coping (the effortful manipulation of unwanted thoughts and feelings) and acceptance-based coping (a defenseless acknowledgement and reception of distress). They found that contrary to the belief that Asian Americans would employ more acceptance-based coping due to the mindfulness practices of Buddhism, Asian Americans used less acceptance-based strategies and more control-focused strategies than their European American counterparts, and that the endorsement of Buddhism or Christianity did not demonstrate any difference in the use of acceptance-based strategies. Furthermore, for both groups, acceptance was related to greater
psychological health, while control was related to decreased psychological health.

Another study found that Asians and European Americans used less confrontive and positive reappraisal strategies to cope with sadness than multiethnic individuals (Vandervoort, 2001). They explained that Asians and European Americans both may have lower use of positive reappraisal because of their Buddhist and Christian beliefs, which endorse ideas of accepting suffering, whereas their multiethnic group, which predominantly included Native Hawaiians, may be influenced by the cultural idea that there is a complimentary positive force to every negative force. All in all, while there are some discrepancies in the reported differences between Asian Americans and European Americans on coping strategies, in general, Asian Americans demonstrate more passive or internal forms of coping than their European American counterparts.

**Attributions.** In addition to culturally bound values, Asians/Asian Americans coping may also be influenced by individual attributions to the stressor, including perceptions of the stressor’s cause and burden, and one’s dispositional optimism/pessimism. Wong et al. (2010) examined the relationship between attributions about depression and coping mechanisms, using Brickman et al.’s (1982) framework of responsibility attributions. This model purports that the type of coping a person uses is determined by his/her attribution of the cause of the stressor and where they deem the responsibility to lie in attending to such stressor. They found that attribution of cause mediated the relationship between adherence to Asian values and coping. Those who strongly adhered to Asian values were more likely to attribute the cause of depression to internal factors while using disengagement strategies more and engagement coping strategies less. One hypothesis is that stronger beliefs in internal attributions may be associated with stigma and
shame (Stepleman, Darcy, & Tracey, 2005). On the other hand, Asian Americans who endorsed an external attribution and an internal solution attribution were more likely to prefer engagement coping strategies. Thus, this research highlights how culture may impact the attribution of the stressor and subsequent coping strategies.

Besides attribution of the cause, research has also examined the attribution of the burden of the stressor. For instance, Bjorck et al. (2001) conducted a quantitative study about the relationship between appraisal of the impact of the stressor to coping strategies among Korean, Filipino, and European American protestant young adults. Results revealed that both Asian Americans groups deemed their stressors as more challenging than European Americans, and Korean Americans also associated greater losses with their stressors. Furthermore, Koreans and Filipino Americans endorsed more passive coping behaviors (accepting responsibility, religious coping, distancing, and escape-avoidance) than Caucasians. Authors propose that this difference may be due to the idea that Eastern values suggest compliance with authority and submission to fate in dealing with problems, whereas Western individualism and self-assertion encourages taking control over and changing one’s situation, which may lead to more active coping styles and a decreased appraisal of loss. Interestingly however, problem-solving strategies were endorsed more heavily among Filipinos than Caucasians.

It has been suggested that different cultures may yield different patterns in the relationship between coping and psychological well-being. For instance, while greater pessimism was a better predictor of depression for European Americans, lack of optimism was more salient for Asian Americans (Chang, 1996). Furthermore, optimism has been linked with more adaptive, engaged coping strategies (e.g. problems solving and cognitive restructuring) whereas pessimism
has been linked with more maladaptive, disengaged coping activities in the general populations (e.g. problem avoidance and social withdrawal; Chang, 1996; Long & Sangster, 1993; Scheier & Carver, 1992). Thus, attribution of the stressor, including optimism and pessimism may affect the choice of coping strategy, which has implications upon devising or adjusting more culturally appropriate treatments to different cultural groups. For instance, whereas the mechanism of change in cognitive therapy may be refuting maladaptive negative beliefs, Chang (1996) suggests that from the current findings, instilling optimism may be more useful than challenging pessimism for Asian Americans in which this is more predictive of mental health.

**Social Support.** Another aspect of cross-cultural literature that has gained attention is the use of social support. Social support is a coping construct involving three aspects: (1) Information support (i.e. offering of clarification and resources); (2) Instrumental support (i.e. tangible assistance such as caregiving help); and (3) Emotional support (i.e. reassurance and warmth; Taylor, Sherman, et al., 2004). Although it seems intuitive that Asians would tend to utilize more social support because Asians often have an interdependent identity as shaped by their collectivistic culture, studies have found that Asian and Asian Americans utilize social support less than European American counterparts (Kim, Sherman, & Taylor, 2008; Taylor, Sherman, et al., 2004). Concerning generational comparisons, Asian nationals and immigrants were less likely to report eliciting social support to cope with stress than subsequent-generation Asians (Taylor, Sherman, et al., 2004).

Taylor, Sherman, et al. (2004) propose that this paradox may be explained by the view of the self’s goals in relationship to goals of the relationship. For collectivistic cultures, this may mean that individual goals are to pursue the interests of relationships. Kim et al. (2006) showed
that in comparison to European American groups, Asian Americans’ consideration for relational implications were more salient in their utilization of social support. Thus, seeking help from others may be perceived as causing a potential strain in their relationships or burden on others, which is subsequently viewed as less effective and is utilized less (Bolger, Zuckerman, & Kessler, 2000; Kim et al., 2006; Markus, Mullally, & Kitayama, 1997). Furthermore, self-expression and self-disclosure are also less valued in Asian cultures due to fears of losing face. Although Asian Americans participants reported seeking help from family and friends than professionals, another 37% of the group preferred keeping their problems to themselves, while participants tended to have positive attitudes towards dealing with mental health problems alone (Yeh & Wang, 2000). Zander (1983) explains this attitude for similar reasons as stated before—that there is a negative stigma against emotional expression (i.e. showing weakness), and it may result in the disruption of group harmony. Chu, Kim, and Sherman (2008) found that those who utilized social support less also rendered negative evaluation towards the behavior. Thus, it seems apparent that seeking social support as a coping mechanism may not only be less endorsed, but also viewed negatively and may be discouraged. Taylor, Sherman, et al. (2004) did a second study to observe the related explanations of this finding that Asians tend to endorse less social support. The reasons that Asian Americans were deterred from using social support were that they wanted to take responsibility to take care of their own problem and did not want to disrupt group harmony, make the problem worse by disclosing, receive negative evaluation from others, or feel embarrassed.

Another explanation to the lowered use of social support by Asian Americans may be due to their lack of social support resources that they are accustomed to in the United States. For
instance, Luong, Yoder, and Canham (2009) explained that Southeast Asians are accustomed to living with extended family members in close proximity. However, many immigrants move only with their nuclear family. Thus, the majority of the participants in their study did not mention relying on extended family members for social support, whilst many of them also expressed resentment about the lack of support from their spouses, and found that the school system was their most prominent source of social support.

Although the majority of studies suggest that Asian and Asian Americans report less use of social support compared to European Americans, there are a minority of studies that show no difference between groups (Chang, 1996). In a qualitative study exploring the coping mechanism of Chinese mothers’ adjustment to the demands of early motherhood, Ngai (2011) noted that although self-reliance was also a prominent coping strategy, they also sought emotional and practical support from their families and or faith communities. Thus, it is possible that the types of social support used during times of stress is a differentiating factor, wherein Asians/Asian Americans are more likely to rely on close in-group members, rather than friends and professionals (Ngai, 2001). Kim et al. (2008) alternatively suggest that they may use social support in a different and culturally appropriate way. They found that perceived or implicit social support, without having to self-disclose and burden others, is more beneficial than explicit support for Asian participants. This notion was also supported by Taylor, Welch, Kim, and Sherman’s (2007) experiment which showed biological evidence of higher stress of Asians in explicit seeking compared to implicit support seeking, which was the opposite in their European American counterparts. Religious practices have also been seen to be an important coping
mechanism for Asian and Asian Americans (Banerjee et al., 2011).

There is not much literature on coping amongst Pacific Islander cultures, however, in Torsch and Xueqin Ma’s (2000) study, they revealed coping strategy themes that arose in qualitative interviews with elder Chinese Americans and Chamorros of Guam. Because they believed illness could be caused by the taotaomona (spiritual ancestors), Chamorros mentioned the use of traditional healing practices and the roles of healers called suruhana and suruhanu, whose powers could treat such spiritually caused illness. They also use medicinal natural remedies, body lotions, altered diets, and massage (McMakin, 1978). While these traditional spiritual and healing methods are endorsed particularly by elders in the community, in present culture, there is also the influence of Spanish Catholicism. Thus, as influenced by Spanish Catholicism, people also believe in curing powers of religious figures (God, Jesus, Mary) who hold abilities to transform states of illness, while assisting them with distress (Torsch & Xueqin Ma, 2000).

**African American Coping**

**Religion.** One of the most prominent preferences in dealing with problems or stress for African Americans cited in literature is the use of religion. Compared to other ethnic and racial groups in the United States, African Americans are shown to use religious coping activities more for distress with life events and for mental health difficulties (Constantine, Wilton, Gainor, & Lewis, 2002; Koenig, 1998). Furthermore, the emphasis on religious coping was demonstrated across ages from college students (Chiang, Hunter, Yeh, 2004; Smith & Dust, 2006) to older adults (Lee & Mason, 2013; Lee & Sharpe, 2007). The group of African Americans who participated in religious activities more in Constantine et al.’s (2002) study, used active coping
strategies less to manage their stress, which could be explained by their demonstrated greater reliance on or in collaboration with the Creator to solve problems. Besides direct reliance on God and the use of prayer, African Americans also sought support from church members and the clergy (Lee & Mason, 2013), wherein the social support from the church members served as a community that they perceived as extended family (Rogers-Dulan & Blacher, 1995).

**John Henryism.** The John Henry Active Coping scale was developed by James, Hartnett, and Kalsbeek (1983) to capture culturally specific constructs of active coping strategies in African Americans. “John Henryism” is characteristic of having hard work ethic, determination for success, and the mental and physical strength to utilize withstanding effort to overcome their socioeconomic environment (Fernander, Duran, Saab, Llabre, & Schneiderman, 2003). While the constructs measured by this scale were supported in both African American and European American samples, John Henryism did not predict active coping in the COPE scale for African Americans in the same way that it did for European Americans. Thus, this construct may capture cultural nuances in coping that are unique to African Americans (Fernander et al., 2003). Additionally, there may be a difference in its use by racial group, as influenced by structural inequalities. For example, optimism significantly predicted John Henryism for African Americans, wherein no relationship was found for European Americans. This finding was hypothesized to be due to optimism existing as more salient for a pressing forward attitude in relation to active coping for African Americans, who face systemic disadvantages and oppression. Similarly, John Henryism and active/problem-focused coping were both associated with higher self-efficacy, which may be attributed to the possible prerequisite or facilitation in the belief that their efforts will and can change their situation towards the use of effortful
strategies (Schmeelk-Cone, Zimmerman, & Abelson, 2003; Smith & Dust, 2006). Schmeelk et al. (2003) also showed that the effects of John Henryism as a benefit to mental and physical health was more so limited to African Americans with higher levels of education. Meanwhile, John Henryism was thought to be associated with negative health outcomes (e.g., high blood pressure) for African Americans who have low SES (James et al., 1983). In contrast to the studies that emphasize John Henryism and active coping however, Lee and Mason (2013) found that African Americans used emotional support, denial, and venting more than other cultural groups. However, in conjunction to John Henryism and toughing out hard times in a self-reliant way, there is also cultural value in restraint of disclosure of one’s problems (from others or outside the family) (Matthews et al., 2006). Besides John Henry, there are also images of the “strong Black woman” who promotes resilience and persistence through trying situations, wherein psychological burdens and stress are normalized (Matthews et al., 2006).

Social support. Some posit that the utilization of social networks is the primary coping resource for African Americans (McAdoo, 1982). In fact, there are many studies have indeed shown support for African American reliance and emphasis on social support in dealing with their stressors (Chiang et al., 2004; Constantine, Chen, & Ceesay, 1997; Krause, 2010; Lee & Mason, 2013; Rogers-Dulan & Blacher, 1995). African Americans are closely and widely connected to parents, friends, and community members, including church members and leaders. For example, it was noted that 85% of African American teenage mothers live in households that span three generations (i.e., children, parents, grandparents; Billingsley, 1992). Lee and Mason (2013) found that African Americans used instrumental and emotional support at the same levels as European Americans with nuclear family members, with the addition to seeking support from
religious leaders. Instrumental support refers to the use of one’s social network to help with tangible resources such as caregiving, finances, or transportation.

**Latina/o American Coping**

The Latino coping literature mainly examines coping preferences or uses by applying universal, Western measures and constructs. The WOC-S (Munet-Vilaro, Gregorich, & Folkman, 2002) is a Spanish translated version of the original WOC scale that is suggested to be appropriate for cross-cultural research with diverse Latino populations. Amidst the lack of coping literature specifically for Latino coping, especially that from indigenous standpoints, there are also mixed results regarding Latina/o American preferences towards active or passive coping. Furthermore, nuanced studies examine the influence of cultural gender roles and U.S. acculturation on Latina/o coping styles.

**Gender.** Since gender roles are part of Mexican and Latino culture, it comes to no surprise that research has examined differences of coping styles by gender within this population. One of the widespread notions of gender roles are males who embody the machismo role. Machismo can be described as a stereotypical authoritative, masculine, self-reliant, virile, protector role of the family (Bean & Northrup, 2009; Comas-Diaz, 1989). Furthermore, recent authors found Mexican American men aligning more with caballerismo which embodies a more flexible masculine style—having dignity, collaborative values, honor, and respect (Arciniega, Anderson, Tovar-Blank, & Tracey, 2008). While endorsement in machismo has not been reliably predictive of coping styles of Mexican American men (Arciniega et al., 2008; Ojeda & Liang, 2014), endorsement of caballerismo was correlated with active coping, positive reframing, planning and using humor (Ojeda & Liang, 2014). Females/mothers, on the other hand, embody
marianismo roles, which encompass self-sacrifice, charity, nurturance and managing the family’s spiritual and emotional needs (Bean & Northrup, 2009; Comas-Diaz, 1988; Gil & Vazquez, 1996). Accordingly, females, especially mothers, were found to be more likely to seek family support, emotional coping, and disclose their stressors with others to manage challenging life situations (Kobus & Reyes, 2000).

Orientation towards the family was considered the most challenging life stressor amongst urban Mexican adolescents in Kobus and Reyes’ (2000) study, as also highlighted in Liu, Gonzales, Fernandez, Millsap, and Dumka’s (2011) study. Furthermore, Mexican American women and other Women of Color have especially been known to have important roles in and priorities towards the family (Marin & Marin, 1991; Munsch & Wampler, 1993). To elucidate the interactions of gender roles and culture on coping with family stress, Liu et al. (2011) conducted a study on first-generation Mexican adolescents in the United States. Whereas active coping moderated the effects on internalizing psychological symptoms in high family stress for girls, who often take on more direct responsibilities in family tasks and matters, it did not have a moderating effect for boys, who typically bear more unpredictable burdens such as finances and employment (Liu et al., 2011). Additionally, support-seeking and religious coping reduced internalizing symptoms for girls, but increased them for boys (Liu et al., 2011). This trend was explained by Liu et al. (2011) who proposed the possibility that boys’ use of more emotion-focused methods of coping may be perceived as threatening to their sense of machismo, which requires them to be self-reliant and capable of handling their problems (Raffaelii, & Ontai, 2004). On the other hand, while boys’ use of distraction in high family stress situations was effective in moderating internalizing psychological symptoms, those effects were diminished in
both high and low family stress situations for girls, which highlights females’ active role in family problems. However, Liu et al. (2011) disclaim that the current coping measure (The Children’s Coping Strategies Checklist-2nd Revision; Ayers, Sandler, West, & Roosa, 1996) may not have adequately assessed the distraction methods this population uses, which includes familial activities outside of the family problems themselves, as opposed to isolated activities.

**Acculturation.** Because Latina/os, including Mexican Americans represent a variety of individual cultures and generations, many of them still experience acculturative and bi-cultural stress, especially for those perceived to be or who are immigrants, due to the additive pressures of adjustment to another culture as well as societal prejudice. Ojeda and Liang (2014) studied a group of Mexican American adolescent boys and girls, looking at bicultural stress factors as it related to differences in coping styles. In dealing with bicultural stress, Ojeda and Liang (2014) found that Mexican American men often used passive styles of coping, including behavioral disengagement, humor, and religion. These findings were consistent with previous research (Crockett et al., 2007; Hawley, Chavez, & St. Romain, 2007), and can be explained as sole resort coping mechanisms to deal with social environments such that they have minimal control, where they may experience hopelessness (Stanton-Salazar, 2001). Furthermore, ethnic identity exploration was related to the use of reframing, planning, and active coping, while positive affect towards being Mexican American related to lower substance use to cope (Ojeda & Liang, 2014). In another study, Mexican Americans were overall, quite different from the other two Latino populations (Mexican and Puerto Rican) in their ways of coping (Munet-Vilaro et al., 2002). The Mexican American group demonstrated lower use of confrontive coping and higher use of problem solving, social support, cognitive avoidance, and distancing compared to the other
groups of Latinos, who were interestingly greatly similar to each other across coping strategies (Munet-Vilaro et al., 2002). Munet-Vilaro et al. (2002) hypothesized that their differences may be due to this population’s unique experience of acculturation to the U.S. Therefore, the experience of cultural stress and identity development may have an impact on the uses and preferences towards coping. In support of the acculturation hypothesis, Farley, Galves, Dickinson, and Diaz Perez (2005) showed that compared to European Americans, Mexicans used positive reframing, religion, and denial more, and substance abuse and self-distraction less, while Mexican-Americans displayed intermediary levels of coping strategies between these two groups. Because findings across studies are rather disjointed and varied in their coping constructs and findings between different generational levels to the U.S., further research to examine the effects of bicultural and acculturative distress on coping is needed.

**Active versus passive coping.** While there is limited literature to support a substantive theory, there has been some debate about the preference of Latinos to use active versus passive coping. While Diaz-Guerrero (1967) originally proposed that Mexican Americans endorse more passive styles of coping than European Americans, as he saw self-modification more culturally sanctioned, Negy (1995) points out in a research note that because there were no significant differences on these dimensions between racial group in his study’s sample, his theory may be in fact, erroneous. In support and a much more recent study, Kobus and Reyes (2000) found that Mexican American adolescents very infrequently mentioned the use of passive/emotion-focused strategies (substance use, religion, distraction), and rather mentioned active/problem-focused strategies much more often. However, Negy (1995) also notes the limits of Diaz-Guerrero’s (1967) poor sample size, poor power, and likely bias in his sample limited to inmates.
Furthermore, Negy (1995) notes that because education and active coping were mildly correlated, further investigation is warranted regarding the possibility that coping style may be influenced by socio-economic status more so than cultural variables. Another area of further investigation may be variance by the type of stressor, as Kobus and Reyes (2000) found that Mexican American adolescents preferred using active coping strategies for academic stress and preferred to use emotion-focused strategies for friend stressors, which may highlight situational loci of control.

**Social support.** The research on Latina/o Americans’ use of social support is scarce as well as mixed. On the one hand, Chang (2015) posits from his findings Latino American college students underutilize social support and prefer self-reliance as to avoid burdening others, especially their parents. Explanations given for forbearance were to preserve group harmony, prevent the problem from exacerbating by telling more people, and to avoid negative judgement. In a different sentiment, Chiang et al. (2004) posits that Latino college students indicated that they sought direct and indirect support from their social networks, including parents and friends, in times of distress. In either case, these findings both highlight the interdependent nature of this culture, and their consideration of the self in a family, group, or community.

**Native American Coping**

In general, it has been recognized since coping research became popular that the literature on Native American coping is minimal and neglected (Dinges & Joos, 1988). One article explored Diné (Navajo) perspectives on healing from a multigenerational sample, mentioning that for one, as do other People of Color, most youth did not view professional help seeking as a way of coping with their stress (Goodkind et al., 2015). Instead, they mentioned the use of
talking to and relying on their network of family and friends for support. In addition, about half of Diné parents/elders in Goodkind et al.’s (2015) qualitative study mentioned the use of traditional healing practices including ceremonies, chants, blessings, or healing/prevention methods using medicinal plants and herbs. The most prevalent form of coping however, was prayer, which was practiced in traditional and/or Christian way (Goodkind et al., 2015).

Well-Being

Consistent with the strengths-based approach, coping is often studied as a predictor or mediating/moderating variable in the relationship between stressors and well-being. Well-being has been studied with the practical motive to improve people’s lives. Particularly, well-being has been associated with a number of positive outcomes, including physical health and longevity, social prosperity and satisfaction, and occupational success (Diener & Biswas-Diener, 2008).

Subjective Well-Being

Subjective well-being (SWB) is a general term, indicating a person’s judgment about his/her life, including feelings, engagement and interest towards various domains (e.g. occupational, social, and physical satisfaction and health; Diener & Ryan, 2009). SWB is commonly measured through self-report inventories. While these measures were found to be mood influenced, they were still found to demonstrate reliability over time and convergence with non-self-report forms of measurement. However, Diener and Ryan (2009) argue that non-self-report methods (e.g. observed behaviors, physiological tests) may provide a more thorough assessment of well-being beyond one’s subjective appraisals.

Besides discrepant methods of measuring well-being, there is also unresolved debate regarding competing theories of well-being. One of these debates include the trajectory between
well-being and positive/negative experiences, wherein top-down or trait theorists suggest that a person’s appraisal of their life at a given time will affect the way they interact with the world, which will then lead to subsequent reinforcing experiences. These theories have been derived from cognitive theories that emphasize the influence of thought on one’s affect and experiences. On the other hand, bottom-up or state theories rather suggest that one’s experiences, being positive or negative can influence their perception of their life. Similar to coping literature, well-being research includes debate over whether this construct is as a state or trait, wherein trait theorists posit that well-being is an overall, stable, natural propensity for a person to positively or negatively regard their life and world, while state theorists would argue that a person’s well-being will fluctuate based their current experiences and current mood. There has also been significant support for biological contributions of well-being, including genetic predispositions, temperament, and personality (Diener & Lucas, 1999; Lykken & Tellegen, 1996; Rusting & Larsen, 1997).

Studies have found that despite the lack of consensus regarding the amount of factors contained in the construct of SWB, researchers have at least asserted that it is composed of cognitive and affective parts. Measures that assess the affective component of SWB are the Affect Balance Scale (ABS; Bradburn, 1969) and the Positive and Negative Affect Schedule (PANAS: Watson et al., 1988). These assessments are interested in assessing an individual’s hedonic balance between positive and negative affective states or emotions. The cognitive approach to SWB is also known as life satisfaction, or examining one’s evaluation or satisfaction with different aspects of his/her life, assuming that their outlook will affect their general well-being. The unidimensional scale to assess life satisfaction is the Satisfaction with Life Scale.
(SWLS; Diener et al., 1985), and the multidimensional scale is the Life Satisfaction Index (LSI; Neugarten, Havighurst, & Tobin, 1961).

**Psychological Well-Being**

Ryff (1989) then developed a scale called the Scales of Psychological Well-Being (SPWB) to apply well-being to determine one’s psychological functioning based in humanistic theory, which emphasizes meaning in life and autonomy. In contrast to prior hedonic theories of well-being (i.e, happiness, pleasure, and satisfaction), psychological well is eudaimonic, such that it focuses on fulfilling one’s potential. This measure is comprised of 6 first-order factors including: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth, which all contribute to the overall psychological well-being construct (Ryff, 1989).

Some studies demonstrate mixed findings regarding the factor structure of Ryff’s original 6 factor structure. For instance, one study found that by using item response theory factor analyses, PWB was most reliable for average scoring British women, wherein higher and lower well-being demonstrated less score accuracy. They also proposed a different factor structure (higher-order, 4-factor) than the original model (Abbott, Ploubidis, Huppert, Kuh, & Croudace, 2010). Similarly, Kafka and Kozma (2002) found that SPWB demonstrated poor evidence for the initial factor structure within a Canadian adult sample. These authors also suggest that at most, SPWB is just another predictor amongst other variables, such as one’s environment and personality that predict SWB.

**Social and Relational Well-Being**

Social well-being has also been studied as part of the overall health of a person. Overall,
it is described as a person’s adaptation or adjustment to his/her social environment (Larson, 1993). McDowell and Newell (1987) developed a different conception of social well-being, described as a person’s way of relating to others and society. They purport two constructs of social well-being: social adjustment (i.e. a persons’ overall satisfaction with their relationships and interpersonal performance) and social support (i.e. access to individuals whom a person can rely on).

Keyes (1998) later developed a theory of social well-being that consists of five dimensions: social integration (i.e. feelings of belongingness to one’s society), social contribution (i.e. one’s perceived value in society), social coherence (i.e. evaluation about the sensibility, efficiency, and one’s interest in the world around them), social actualization (i.e. the perception of progress of society), and social acceptance (i.e. the perception of the generalized character of others). These dimensions address how a person considers his/her placement and functioning in society. Keyes (1998) considers social well-being as an “accomplishment” acquired through age and education, as it is correlated with socioeconomic status.

Cross-Cultural Considerations in Well-Being

Well-being has been extensively studied in relation to demographic variables, such as gender, income, education, and age. In addition, the relationship between culture and well-being has also been a popular topic of interest. Studies in this area however, focus more on subjective and psychological well-being, with a dearth in cross-cultural social well-being studies.

Overall, samples from populations of less-industrialized and poorer nations have lower well-being than those from industrialized, wealthier nations (Diener & Suh, 2000). There also seems to be support for certain factors across cultures to be consistently associated with high
well-being, including preserved human rights. There are of course exceptions to the rule, however, in which some cultures from impoverished societies and dismal conditions display high well-being. Rice and Steele (2004) conducted a study to determine the influences of culture on well-being, and found that well-being of subjects in America were comparable to well-being levels in their ancestral cultures. This finding suggests that there are inherent cultural influences on well-being that persist through generations. In addition, above the poverty line, the strength of association between income and well-being diminishes with increasing levels of income (Diener, Ng, & Tov, 2009).

There is also cultural variability regarding well-being’s relationship to self-esteem, and positive versus negative affect, wherein individualistic cultures demonstrate stronger correlations between self-esteem and certain positive affects (e.g. pride, excitement) as more valuable, while collective cultures have weaker correlations with self-esteem and well-being, and find certain negative emotions as important to their well-being (e.g. guilt, calmness) (Diener & Ryan, 2009).

Although there are only a few cross-cultural or multicultural studies on the application of etic measures of well-being, much of this research focuses on the use of these measures for Asian/Asian Americans. Unfortunately, research on well-being for other ethnic and racial groups is largely lacking and could use further development. Studies have often found that Asian Americans demonstrate lower subjective well-being compared to other populations (Diener, Suh, Smith, & Shao, 1995; Kitayama, Markus, & Kurokawa, 2000; Wirtz, Chiu, Diener, & Oishi, 2009). In a study with East Asians (Japanese, Chinese, Koreans), Diener et al. (1995) posited that the relatively lower Asian subjective well-being scores were consistent with ideas of their culturally normative values of positive and negative affect. While positive affect is more
meaningful and desirable for European Americans, Asian Americans place more value on the balance between positive and negative emotions and appraisals and the dialectic within such contradiction (Kitayama et al., 2000; Spencer-Rodgers, Peng, Wang, & Hou, 2004; Wirtz et al., 2009). In fact, Asians may hold negative associations of characteristics assumed by extremely happy people (Suh & Diener, 2006). These beliefs may be influenced by Eastern philosophies (e.g., Buddhism, Taoism, Confucianism) that emphasize the yin-yang dichotomy, suggesting that health should be based on obtaining a harmonious balance of interdependent, opposing forces (Torsch & Xueqin Ma, 2000). From a different perspective, Suh (2007) addresses self-construal as an influencing factor on general affect. He recognizes the effect of collectivistic focus on others (e.g. pressures of being accepted and social comparison) as a situation in which a person’s affect is more vulnerable to change based on contexts and external experiences.

Acculturative stress, including migration conditions, cultural differences, and perceived discrimination were shown to have negative effects on life satisfaction of immigrants to Western countries (Leung, Pe-Pua, & Karnilowicz, 2006; Phinney & Ong, 2002), whereas higher acculturation is associated with increased well-being (Lang, Munoz, Bernal, & Sorensen, 1982). In addition, there is evidence to suggest that bi-culturalism, or orientation towards both one’s host and indigenous culture is linked to higher psychological well-being and adjustment in Asian and Latino Americans (Baker, Soto, Perez, and Lee, 2012; Lang et al., 1982; Ying, 1995).

**New Directions in Well-Being**

Given that research demonstrates variation of well-being between cultural groups, indigenous approaches to assessing well-being have recently emerged in attempts to address cultural differences that may account for these discrepancies. Native American perceptions of
well-being across existing generations, emphasize the importance of the connection to one’s land, which helps to restore not only personal well-being but also facilitates connection to one’s culture and community (Goodkind et al., 2015). In addition, Chamorro elders from Guam also consider the importance of holistic health between the mind, body, and spirit, as well as collectivistic strength in their relationships with family members, elders, and ancestors’ spirits, with spiritual foundations (Torsch & Xueqin Ma, 2000).

From an emic perspective, McCubbin, McCubbin, Zhang, Kehl, and Strom (2013) developed a measure of well-being based in the culture of the indigenous communities of Hawaii. From this culture, well-being is a relationally, rather than individually based. Relational well-being is an ecological and holistic perspective that expands beyond one’s connection to society or individual well-being, and encompasses the domains of nature, spirituality, and ancestral connections, amongst other social networks.

Alternatively, Lu and Gilmour (2006) have developed a well-being measure using Yang’s (2000) “cross-cultural indigenous” approach, which combines both etic and emic approaches. The measures they derived are called the Individual-Oriented SWB (ISWB) and Socially Oriented SWB (SSWB) scales (ISSWB). These measures demonstrate good psychometric properties (e.g. internal consistency reliability, test-retest reliability, convergent and discriminant validity; Lu & Gilmour, 2006). As predicted, their Chinese participants demonstrated stronger SSWB, while American participants demonstrated stronger ISWB. Thus, the use of new emic measures that address well-being from culturally relevant perspectives may find utility in future
General Coping and Well-Being of Parents of CWD

Coping Predictors of Well-Being

There have been few consistent findings regarding general coping studies of parents of CWD. One of these general findings is that problem-focused coping is found to be more strongly correlated with parent well-being than emotion-focused coping (Bradley et al., 1991; Judge, 1998). Studies also often cite the importance of ascribing a positive meaning to the child’s disability or caregiving experience in developing positive parent adjustment. In King et al. (2006), the experience of raising a child with a developmental disability thrusts parents to examine and become aware of their worldviews, goals, and what is important to them in life. There were many ways that parents changed their perspectives: developing broader world views, positively viewing the situation and how it has impacted them (e.g. made them appreciate life differently), seeing strengths in their child, changing their values, and changing their priorities. In a follow-up study, King, Baxter, Rosenbaum, Zwaigenbaum, and Bates (2009) studied parents of CWD who were transitioning into elementary or high school. Worldview themes that were explicited from the previous study were: optimism (hope for future, openness to experience), acceptance/appreciation (for disability and associated challenges), and striving to overcome those challenges. Parents also perceived that social stigma affected them more during the initial diagnosis phase and that their relationships within the family with extended family members had improved over time as a result of the child’s disability (Gray, 2002; Gray, 2006).

While problem-focused coping and reappraisal of the situation has consistently yielded positive well-being outcomes, Darbyshir and Kroese’s (2012) literature review on parents of
children with intellectual disabilities found mixed results regarding the relationship with psychological well-being and social support, with some studies finding a significant relationship, while others did not. The presence and use of social support of CWD in general, has been related to positive parent adjustment, however (Dunst, Trivette, & Jodry, 1997; Taanila, Syrjala, Kokkonen, and Jarvelin, 2002). Likewise, Skok, Harvey, and Reddihough (2006) studied mothers of children with cerebral palsy and found that while the severity of the disability did not predict well-being, both perceived stress and perceived social support had significant predictive effects. In terms of limitations, Darbyshir and Kroese (2012) note that there is a lack of well-being measures specific to parents of CWD, resulting in unstandardized and inconsistent assessment techniques between these studies in this area.

Mediating and Moderating Variables

Taken together, while the use of coping towards well-being and positive adjustment is widely supported, there are many other mediating and moderating factors that affect this relationship or coexisting predictor variables of parent outcomes that should be considered. First, studies have found differential effects of the adjustment of mothers and fathers in caretaking. Mothers have been found to experience higher subjective distress than fathers (Gerstein, Crnic, Blacher, & Baker, 2009) and lower well-being (Olsson & Hwang, 2008). In fact, Gerstein et al. (2009) found that the relationship between daily stress and psychological well-being was not significant for fathers of children with an intellectual disability. In addition, child behavior problems were only associated with psychological distress for mothers (Llyod & Hastings, 2009). Reasons for these findings may be that mothers are often found to spend more time with their children than fathers and are seen as the primary caregivers (Hogan, Shandra, & Msall,
In fact, 55% of mothers of CWD worked at home to accommodate for the child’s needs (Gerstein et al., 2009). Furthermore, this trend is observed in all caretaking, regardless of disability status, and cultural differences (Gerstein et al., 2009).

Besides parent gender, one of the other most robust predictors of parent well-being/psychological outcomes is the presence of child behavior problems, in that increased child behavior problems led to decreased parental well-being (Baker et al., 2005; Kersh et al., 2006; King, King, Rosenbaum, & Goffin, 1999; Llyod and Hastings, 2009). Other common predictor variables that were found to increase well-being were decreased economic hardship (Kersh et al., 2006; Mahoney et al., 1992) and increased optimism or hope (Baker et al., 2005; Lewis et al., 2006; Llyod & Hastings, 2009; Taanila et al., 2002). However, Olsson & Hwang (2008) demonstrate that socio-economic status has no relation to parental depression. Lastly, having an internal locus of control was also predictive of positive psychological adjustment in parents of CWD, particularly in the sense that parents felt efficacious in managing the behavior of their child (Hill & Rose, 2009; Llyod and Hastings, 2009).

Asian/Asian American Parents of CWD

Previous literature on the intersection between ethnicity and disability exists from the late 1980s through the current decade. Most studies involve qualitative interviews with open-ended questions in aim of ascertaining a thorough emic perspective of the experience of Asian families with disabilities. Samples have been typically obtained by targeting this population through convenience sampling in community/social service agencies.

Western cultures may adopt a “medical” attribution of disability, wherein the disability is caused by external mechanisms (e.g. genetics, prenatal environment) and is solved through
external means (e.g. medical treatments and procedures; Brickman et al., 1982). However, other cultures may have different conceptions of the meaning, etiology, and treatment of “disability.” Previous literature on Asian populations suggests the following common themes: karma, behaviors of parents during pregnancy, and the will of God.

**Perceptions of Disability and Stigma**

Multicultural studies of various racial groups in the U.S. demonstrated that Asian Americans hold the strongest stigma towards persons with disabilities compared to racial group counterparts (Saetermoe et al., 2001; Scior et al., 2013). Shame towards disabilities may derive from deviations of collectivistic values of conformity and hindered abilities to make contributions to society (Chan et al., 1988; Ng, 1997). These negative reactions seem to be related to the cultural attributions to the disability, and thus, CWD are often concealed within Asian families for fear of isolation (Zhou, 2000).

**Karma.** Many studies with Chinese and Taiwanese populations note the role of karma as the cause of their child’s disability as influenced by Buddhist philosophy. Dependent upon the belief of reincarnation, in which the soul transmigrates in the existence of one form of life to another, karma is the concept that one’s present life is impacted by actions in the past. Therefore, the manifested disability in present life would be considered punishment for moral wrongdoing in the disabled person’s past life or from their ancestors (Liu, 2005). In Huang, Fried, and Hsu’s (2009) qualitative study, examining the attitudes of Taiwanese mothers of children with mental retardation, 80% of participants ascribe their child’s disability to karma. Different variations of the implication of karma included: mothers thinking they did something wrong in their past life, that they owed a debt in their previous lives which is repaid through their children, or that the
child was there to pay a debt of gratitude through his/her disability. The remaining participants did not believe in the idea of karma at all as they either ascribed it to chance or placed no emphasis on the cause of the disability altogether. In a qualitative study on Chinese American families, several parents thought that their child’s condition was due to something that they or their spouse did in the past, taking full responsibility for the cause of their disability (Ryan & Smith, 1989). From another perspective, a case study of a Vietnamese American family found that these parents ascribed their son’s disability to karma from wrongdoings of their ancestors in the past (Sage & Jegatheesan, 2010). Thus, although the idea of karma is prevalent throughout the Chinese and greater East Asian culture, the interpretations of karma in the cause of disability greatly varies.

**Cultural beliefs.** Besides karma, another commonly cited attribution of disability in Asians is superstition regarding the behavior of the mothers during their pregnancy. For example, in a study with Korean and Korean American parents, participants believed in the mistakes in Tae Gyo, which are cultural prenatal practices that presume to influence their child’s health (Cho et al., 2000). Research also found that Bangladeshi mothers also assumed responsibility for their child’s disability due to something that they did. For example, one mother noted that she believed that “hard labor” or “fall[ing] down” during pregnancy could cause a child’s disability, noting a fall that she took during a rainy day in the past while she was pregnant (Maloni et al., 2010).

**Will of God or fate.** Although the influence of karma and traditional superstitions may largely influence the perceptions and reactions to disability for traditional Asian populations, for Asian Americans cultures where religion is a strong influence, the will of God was a recurrent
theme. From a broader perspective, Diken (2006) noted that disability was found as a blessing, punishment, test, or other unknown purpose from God, in examining Mexican American, Chinese American, Arab, and Jewish families. Within differing Asian cultures, South Asians considered their child’s disability as a gift from God (Daudji et al., 2011), rather than as a punishment, as evident with Bangladeshis (Maloni et al., 2010). Cho et al. (2000) also found that the Christian Korean and Korean American participants in their study found positive meaning in their attribution of their child’s disability to an ordained purpose of God. Furthermore, these participants felt gratitude for the spiritual growth that was gained as a result of the process of grieving and taking care of a CWD.

**Additional influences.** Other influences on Asian/Asian Americans’ perception of disabilities that were less commonly cited were: the idea of acts of fate in general (unrelated to God, religion, or karma), physical agents such as birth-control pills, and an imbalance of Chinese cosmology (Ryan & Smith, 1989). The Chinese cosmology attribution encompasses the idea of Yin (cold) and Yang (hot), which are co-existing complementary forces in all of existence. Chinese American families who ascribed their child’s disability to “high fevers,” were suspected to be operating under this conceptualization (Ryan & Smith, 1989)—suggesting predominance in Yang forces, and lacking of Yin forces. Illness in general is thus thought to be caused by an imbalance of yin and yang forces, which must be remedied by restoring such balance (Torsch & Xueqin Ma, 2000). In addition to the holistic mind-body connection that other indigenous cultures endorse, Chamorro elders from Guam also consider spirituality as a determinant of health or illness in general, wherein the ancestor spirits, taotaomona, could cause mental or
physical illness, especially for pregnant women (Torsch & Xueqin Ma, 2000).

**Parental Reactions**

**Normalization of the disability.** Despite the attributions of shame associated with disability, there are also a contrasting number of Asian parents who reject the idea of “disability” and rather deem the child’s condition as temporary, with hope that treatment will make the child “normal” again (Daudji et al., 2011; Maloni et al., 2010). The common motivation for this hope of normalization is for their children to be able to receive and education and independence enough to assuage stigmatization, and foster integration into society (Daudji et al., 2011; Maloni et al., 2010). In fact, in a study conducted with Chinese American families, Parette, Chuang, and Huer (2004) posit that in contrast to other studies of Chinese participants, their participants did not demonstrate feelings of shame attached to their child’s diagnosis, and were generally very accepting and held relatively positive attitudes about their child’s condition. A similar hope for improvement of symptoms was evident, with heavy reliance on community treatment services. Authors purported that higher acculturation may have contributed to this contradiction.

**Expectations of their child.** While there are parents who resist the label of a disability, there are also parents who have lower expectations of their children in accepting their child’s perceived limitations. For instance, Ly (2008) found that Asian Americans parents rated their child’s performance as lower and had lower expectations for future success of their CWD on a problem-solving puzzle task than their European American counterparts. Also, Asian Americans parents attributed their child’s performance to lower ability and effort, while experiencing less sympathy and more anger and blame towards their child’s performance. Interestingly however, they also endorsed similar beliefs with hypothetical typically developing children, suggesting
that humility and modesty may have an overall effect in the perception of their child’s performance despite the disability. Also, Asian Americans parents were more likely to offer help with perceived lower effort of their child, which was dissimilar to their European American counterparts who only helped more with perceiving lower ability. This may ultimately suggest that although functional expectations seem to be lower, Asian Americans parents still expect and encourage effort from their child.

**Influences on caregiving attitudes.** The collectivistic values that create environments where stigma and shame may be more negatively impactful than in individualistic cultures also create positive social environments of cooperation and communal welfare. For instance, parents who adhere to traditional values feel obliged to take care of their CWD because of their perceived fault in the role of their child’s condition, or the debt that they purport to owe from karma (Ryan & Smith, 1989). In addition, the Confucian values of filial piety expect that persons with disabilities be taken care of by their families; otherwise they would suffer public shame (Ryan & Smith, 1989). In Sage and Jegatheesan’s (2010) cross-cultural study comparing an Asian American family and a European American family who both had a child with autism, authors found that both parents expected their oldest child to be accommodating to their younger sibling with a disability. However, while the European American family did not impose any responsibilities or roles onto the older child, the Vietnamese parents expected the older child to set a good example, and to be nice to his younger brother all the time. Furthermore, the Vietnamese older brother was not told of his younger brother’s disability until two years after the diagnosis because his parents were afraid that he would reject his younger brother and/or tell other community members of about the disability. On the other hand, the European American
family informed their eldest child about the disability of their younger child as soon as the diagnosis was made, and continually explained his condition to him.

**Seeking of Services**

Taken together, the superstitious, supernatural, and religious indigenous attributions of disability often come into conflict with the Western biomedical diagnosis and etiology of disability that renders specific biological causes and permanency in conditions (Ryan & Smith, 1989). The heightened caretaking responsibility that has been shown in Asian Americans culture may also avert them from seeking outside social services available in the community (Choi & Wynne, 2000). Furthermore, the value of privacy in the family may also limit the amount of disclosure that practitioners may need in forming diagnoses or treatment plans (Choi & Wynne, 2000). In light of these considerations, the overall picture of literature suggests that there tends to be a mix between endorsement of biomedical treatments as well as traditional healing methods amongst the Asian/Asian Americans populations as a group and within their individual perspective or help seeking behaviors as well (Diken, 2006; Maloni et al., 2010; Ryan & Smith, 1989). Examples of alternative traditional healing practices that Asians engaged in were: religious engagement in Korean culture (Cho et al., 2000), mediums to ward evil spirits, acupuncture, bangles to bring good luck in Chinese culture (Ryan & Smith, 1989), and homeopaths, village healers, massage oil, dietary restrictions, and wearing lockets in Bangladeshi culture (Maloni et al., 2010).

**African Americans Parents of CWD**

**Impacts and Caregiving Relationships**

African American parents raising CWD are a unique group that faces a number of
additive stressors to the caregiving process, including financial strain, neighborhood risks, systemic oppression, and societal stigma. African Americans hold the highest incidence of disability among all ethnic/racial groups in the U.S. (Alston & Turner, 1994). The responsibility of caregiving often rests upon mothers (Borum, 2007; Heflinger & Taylor-Richardson, 2004). Interestingly, African American mothers perceived less negative impact than European American mothers in having a CWD (Bishop et al., 2007). Another study found that African American parents with CWD had increased somatic symptoms, but comparable positive affect as African American parents without a CWD (Ha et al., 2011). Both authors explained the minimal impacts of African American parents of CWDs by hypothesizing that parents in this group deal with a multitude of environmental stressors that may relatively overshadow the stress that comes from raising a CWD (Bishop et al., 2007; Ha et al., 2011). From another perspective, African Americans may be less likely to perceive having their CWD as a burden because it is perceived as an illness carried by the family instead of by the individual (Bloch, 1983).

Furthermore, in low income environments, there are more African American grandparent caregivers (along with Latina/o’s) of children with developmental disabilities than other racial groups in the U.S (Fuller-Thomson, & Minkler, 2000; Kolomer, McCallion, & Janicki, 2002). With such neighborhood risks, the most common reasons for grandparents’ caring for their grandchildren with CWD were that the child’s parent was involved with substance use, they didn’t want the child to go into foster care, or that the child’s parents died (Kolomer et al., 2002). For these African American grandparents caring for a CWD, their level of depressive symptoms compared to other grandparents of CWD, but were higher than grandparent caregivers without a CWD, as explained by factors (e.g., unemployment, single, low education) related to service
barriers and increased burden (Kolomer et al., 2002).

**Oppression/Stigma**

African American caregivers of CWD face additional oppressive forces in light of their child’s disability, including racism experienced within disability communities and prejudice against persons with disabilities within their social networks and cultural community (Borum, 2007). In African American culture, there is a preference towards coping mechanisms outside of seeking professional services for mental health concerns (Snowden, 2003). This group associates shame, embarrassment, and weakness in seeking professional mental health services (Matthews et al., 2006; Snowden, 2001). Additionally, professional mental health services are looked down upon as a luxury for the rich for African Americans, while the poor who seek such services are seen as “crazy” (Matthews et al., 2006).

Despite the stigma from outside and within their communities, African American mothers with deaf children hoped that their children could learn about their own African American culture, become aware of the superimposed dominant culture in the U.S., and form a connection with other children who are deaf (Borum, 2007). Other studies remain varied in terms of the perception of stigma against persons with mental illness or disability within the African American community, with some indicating that it is high (Gary, 2005; Lindsey et al., 2006; Matthews et al., 2006) and some indicating that it is low (Corrigan, Edwards, Green, Diwan, & Penn, 2001; McCallion et al., 1997) compared to other cultural groups in the U.S.

**Religious Coping**

Prayer was often mentioned as a culturally endorsed way of dealing with stress and mental health issues (Taylor, Chatters, et al., 2004; Ward et al., 2009) for African Americans. As
religious engagement appears to be one of the primary coping mechanisms African Americans use to deal with having a CWD, it also creates a lens from which to interpret the disability (Matthews et al., 2006; Rogers-Dulan & Blacher, 1995; Terhune, 2005; Wilson & Miles, 2001). One way that religion is used for this population is to make sense of the child’s disability. First, having a CWD may be deemed as a manageable challenge due to the belief that all children are important according to religious beliefs (Hill, 1993; Marion, 1980). Even though there are also negative appraisals through the lens of religion that can be created about disability, most families that participate in religious activities ascribe positive, accepting, and meaningful interpretations of their disability, believing that they are a creation of God (Krauss & Seltzer, 1993; Rogers-Dulan & Blacher, 1995). However, the use of faith and religion to interpret meaning in this group is not always straightforward. For instance, In Wilson and Miles’ (2001) qualitative study, they found that some African American mothers or chronically ill children experienced tension and a rough relationship with their spirituality during their child’s early hospitalization, while other mentioned that from such experience, their faith has grown and become stronger. Prayer as practiced by the parents themselves, as well as collectively by family or community members for their child elicited strength, hope, and comfort through such time of uncertainty for their child’s health. It was further explained that prayer brought hope and relief in the sense that their child’s fate was in the hands of God (Wilson & Miles, 2001). Additionally, belief in God can bring comfort to parents with the idea that God will help them get through difficult times (Rogers-Dulan & Blacher, 1995). Another study alternatively discovered and explored the diversity in the ways that African American parents perceived and coped with having a CWD, noting two separate categories of parents—one that was secular and one that was spiritual (Terhune, 2005).
In this study, parents ascribing to the secular perspective placed emphasis on promoting the child’s independence, while relying on professional help. To these parents, their child’s disability label negatively affected their perception, to which they appraised as a burden. On the other hand, parents ascribing to the spiritual perspective placed emphasis on their child building relationships within his/her community, while relying on the church network and God. These parents viewed their child as their purpose for living, to which their child’s diagnosis was only used to navigate the system of mental health services, not affecting their own view of their child. Amongst both groups, caregivers’ relationship with God varied greatly (Terhune, 2005).

Similarly, Matthews et al. (2006) found that attributions to mental illness ranged from stress and trauma to religious reasons (i.e., caused by demon/spirit), with some believing it was a chronic, largely treatable condition, and other believing it was curable through religious intervention. Another study found that African American women also viewed mental illness to be chronic, with unfavorable outcomes, caused by general (e.g., trauma, biological, environmental) and societal (e.g., racism) stress or aging (Ward et al., 2009). Therefore, African American parents may have varying levels of beliefs towards culturally informed or biomedical models of disability, which places importance on assessing for individual perspectives and needs amongst parents (Terhune, 2005).

**Social Support**

The literature on African American caregivers of CWD also highlights their availability and use of a strong support network as a common coping resource, which sheds light on their interdependent values from a collectivistic culture. It was noted that African Americans only seek the help from people outside their existing network of support when distress or problems in
their lives persist beyond use of such resources (McAdoo, 1982). Illustrating the extensive nature of their social support network, African Americans were shown to utilize instrumental and financial support from extended family members, which reduce caregiver, financial, and health barrier burden (Crnic, Friedrich, & Greenberg, 1983; Ellison, 1990). They also deem church members as another source of support, just like family (Ha et al., 2011; Rogers-Dulan & Blacher, 1995). The effects of this support are shown to be beneficial, as it has been commonly found that increased family/kin support relates to better mental health, happiness, and life satisfaction (Ellison, 1990; Ha et al., 2011).

**Latina/o American Caregivers of CWD**

**Impacts and Caregiving Relationships**

Latina/o American caregivers of CWD are found to be highly involved in their child’s life and the caregiving process, with one study finding that mothers reportedly became very close to their children during infancy after the initial shock and mourning of their diagnoses (Ramirez Garcia, Hernandez, & Dorian, 2009; Sheets, Baty, Carlos Vazquez, Carey, & Hobson, 2012). Studies have found that Latina mothers, in comparison to European American mothers with CWD have higher levels of depression (Blacher & McIntyre, 2006; Blacher, Lopez, Shapiro, & Fusco, 1997). Blacher and McIntyre (2006) also found that Latina American mothers had lower morale in addition to higher depression, yet perceived a higher positive impact in having their child. Additionally, Blacher, Begum, Marcoulides, and Baker (2013) found that as compared to European American mothers of children with intellectual disabilities, Latina American mothers did not show decline in their perception of positive impacts of having their child over time. This paradox may be accounted for by the marianismo values of Latina culture, which emphasizes
self-sacrifice, bringing value and satisfaction in motherhood (Blacher & McIntyre, 2006), and the value of aguantar, which embodies endurance through hardship (Zea et al., 1994). While these principles may be demonstrated in other People of Color, Latina mothers were thought to embody especially strong values in the self-sacrifice and devotion regard, indicating morality, as influenced by their role model of Mary from the Catholic Church (Skinner, Bailey, Correa, & Rodriguez, 1999). In fact, Latina mothers reported positive experiences and meaning they acquired through raising their CWD, noting that they have become a better mother and person (Skinner et al., 1999). To illustrate their dedication and commitment to parenting, Latina/os in California were found to use hardly any out of home residency programs of care for their CWD through their child’s adulthood, which aligns with their perception of parenting as an extended role throughout their child’s life (Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005; Shapiro, Monzo, Rueda, Gomez, & Blacher, 2004). While this perspective may help mothers accept their child’s disability and their role as a parent, it may also risk overburden and compromising one’s health (Brown, Abe-Kim, & Barrio, 2003). However, the effects of overburden may vary by acculturation, as Eisenhower and Blacher (2006) found that having multiple family roles (employment, parenting, being married) was only positively related to well-being for highly acculturated Latina American mothers, whereas lower acculturated mothers, who may have had more connection to marianismo self-sacrifice and acculturative stress, demonstrated no relationship between roles and well-being. Furthermore, the study demonstrated particular risk of low well-being for unemployed and unmarried Latina mothers (Eisenhower & Blacher, 2006).

Although Latina/o caregiving research is limited in the focus on parents and mothers in particular, one study examined the effects of Latina/o grandparents raising a grandchild with a
CWD. Burnette (2000) found that compared to Latina/o grandparent caregivers in general, those who cared for a CWD endorsed increased depressive symptoms, highlighting the additional demands and health impacts this role involves. Burnette (2000) explained further that while these grandparents were widely connected to a social support network, it was difficult for them to sustain consistent instrumental caregiving help, while also having unmet community service needs. These stressors and negative mental health impacts were similarly demonstrated in African American grandparent caregivers of CWD (Kolomer et al., 2002).

Social Support

As a part of a collectivistic culture, Latinos value familialism, in which the family’s needs come before an individual’s, wherein the family diverts collaborative care towards the family member in need at any given time (Zea et al., 1994). This value has been found to be more prevalent in Latino families compared to non-Latinos (Almeida, Molnar, Kawachi, & Subramanian, 2009), and was related to greater family quality of life (i.e., family interaction quality, meeting child’s needs, emotional well-being of family members) (Cohen, Holloway, Dominguez-Pareto, & Kuppermann, 2014). Smart and Smart (1991) describe Mexican American families as being supportive and protective of members in their family who have disabilities. Family cohesion and perceived family member support were found to be protective factors against caregiver burden, indicating the value placed on family support (Blacher et al., 1997; Magaña, 1999). Regarding the particular uses and impacts of different kinds of measured social support in such families, studies show that Latina mothers’ perceptions of emotional support from their partners was positively related to family quality of life, life satisfaction, and parenting self-efficacy (Cohen et al., 2014; Cohen et al., 2015), and was considered the most prevalent
source of support (Sheets et al., 2012). The support and presence from their husbands were particularly salient in receiving the initial news of their child’s diagnosis (Sheets et al., 2012). While the self-efficacy and life satisfaction finding was comparable in Latina and European American mothers (Cohen et al., 2015), authors purport that a stronger effect for parenting self-efficacy existed for Latina mothers because they may not receive emotional support as often as with European American mothers, or because they may place more emphasis on their partner’s support, wherein community support is less visible. Studies also found that instrumental support was not related to family quality of life or parenting self-efficacy, while perceived support from other family members predicted life satisfaction (Cohen et al., 2014; Cohen et al., 2015). Authors explain that the minimal relation of instrumental support to well-being outcomes may be due to the familiar and assumed role of mothers in their existing family dynamic (Cohen et al., 2014; Cohen et al., 2015), wherein emotional distress may be a more difficult stressor to manage than caregiving duties.

**Reactions and Stigma**

Mexican American caregivers of children with schizophrenia reacted to their child’s diagnosis of mental illness with sadness rather than anger (Guarnaccia, Park, Dechamps, Milstein, & Argiles, 1992). In reaction to hearing that their children were diagnosed with Down Syndrome, Latina mothers indicated that rather than hearing about the impairments and negative aspects of their child’s condition, they also wanted to hear positive things and relied on their husband as a comfort and support with the news (Sheets et al., 2012). Furthermore, Latina mothers of children with Down Syndrome wished for more comprehensive, slower explanations of their child’s diagnosis with less use of medical jargon and greater facilitation by providers to
connect with the Down Syndrome community (Sheets et al., 2012, Skotko, 2005). While husbands were perceived to be more readily accepting in this qualitative study by mothers (Sheets et al., 2012), it was also hypothesized that they would be more resistant to the idea because of their projections of machismo roles which emphasizes strength and capability, wherein they may perceive the disability as a weakness of their child cannot contribute to the family (Zea et al., 1994). In essence, the disability is “owned” by not the individual, but by the entire family, who share responsibilities of care (Zea et al., 1994).

Latina mothers also noted that in Mexico, the stigma against persons with Down Syndrome is very strong, as mothers are thought to be the cause of their child’s condition. Therefore, there is a need to hide their children from the prejudice of their social environment (Sheets et al., 2012). Thus, in relative comparison to the environment in Mexico, Latina American mothers were grateful that they lived in a country that was accepting of persons with disabilities (Sheets et al., 2012). Despite such cultural stigma, however, the majority of Latina American mothers in a qualitative study described parenting their CWD as a positive and rewarding growth experience (Skinner et al., 1999). Latina parents with CWD had hopes for their children of acquiring bilingual proficiency, receiving an education and doing well in school, obtaining a career, and living independently (Sheets et al., 2012; Wolman, Garwick, Kohrman, & Blum 2001). In addition, compared to European American parents, Latino American parents (in addition to African American parents) hoped for the improvement of their child’s behavioral issues, in order to alleviate family conflict (Wolman et al., 2001).

**Meaning in Religion**

Regarding the way that Latina/o Americans explain the disability of their child varied,
with a frequency of religious explanations in the literature. From an indigenous perspective, mental illness is thought to derive from an imbalance between the mind and body, causing nervios (nerves), as opposed to being attributed to a personality flaw (Guarnaccia et al., 1992). Stigma in their culture comes from the idea that a child’s disability is supernatural or a punishment from God for a family member’s wrongdoing before or during pregnancy (Cruz, 1979; Sheets et al., 2012; Skinner et al., 1999; Zea et al., 1994). However, in Skinner et al.’s (1999) study on Latino American families, they found that among parents who used God in their explanation for their child’s disability, most of them used a more positive narrative, wherein their child was a blessing or gift from God. Positive reasons for God giving them their child are that it was his will, that they were given a challenge that provides them the opportunity to prove the deservingness of spiritual reward, that they were already found to be worthy and capable of parenting this child, or because the experience was an opportunity to improve as a person (Skinner et al., 1999; Zea et al., 1994). Others discussed their experience as transformative in not only personal change and growth, but also in the way that it strengthened their relationship with God (Skinner et al., 1999). Positive religious attributions were reported to improve their bond with their child (Sheets et al., 2012), and serve as a coping resource (Ramirez Garcia et al., 2009) as well. Sheets et al. (2012) found that many of the Latina mothers who had children with Down Syndrome in their study, explained their child’s disability with a combination of religious factors as well as medical ones. Besides the aforementioned religion and indigenous factors, other factors used to explain disability by Latina/o Americans were: environmental, genetic/medical/biological, and natural (e.g., accident) (Hershenson, 1992; Sheets et al., 2012;
Native American Caregivers of CWD

Similar to the coping and well-being literature, there is also a dearth of recent studies on caregivers of CWD in the Native American population. Much of the existing literature of Native American mental health focuses on substance abuse, as opposed to developmental or other types of childhood disabilities. However, in one older study, Anderson (1989) reviewed the perceptions of disability by U.S. cultures, and summarized that due to the multitude of tribes and cultures within the Native American population, in addition to cultural evolution, there is also great variance in their views of disability. Anderson (1989) reported that in general, Native American cultures’ beliefs about health are influenced by religion. There have also been superstitions about taboo behaviors of pregnant women. For example, being cruel to animals, fishing, marrying into one’s matrilineal family, being unfaithful, or getting into arguments during pregnancy are among superstitions that may cause disability or abnormal births (Locust, 1987).

In addition, there is also a lot of variation in what and how each culture deems as a disability. Locust (1987) explained that wherein these communities used to be inclusive of those with disabilities, they have grown to become separated. An important determinant of such exclusion from the community in the Hopi culture may be if the CWD can contribute to society (Locust, 1987). For the Navajo, perceptions are condition specific. Although congenital hip displacement, which is common amongst the Navajo, is not concerning to this society, cleft palate, and especially epilepsy, is fraught with stigma (Anderson, 1989). Females with epilepsy are seen as ineligible to marry and are subject to exploitation from male relatives due to the belief that seizures are caused by sibling incest. For these reasons, wealthy families were found
to conceal their child from the community to protect them in isolation, and acculturated families treated their seizures through medication (Kunitz, 1983). However, in another multicultural study that included various People of Color within and outside of the U.S., Native Americans (along with African Americans) were deemed the least likely to hide their family member with a disability (McCallion et al., 1997), highlighting the variation within and between cultural experiences, inconsistencies in research regarding stigma and disclosure, and possible effects of cultural evolution or acculturated values.

Considering that these are outdated studies and that acculturation since the 1980s may have prompted significant change in cultural perspectives and practices, further research on the current attributions of disability and how stigma influences families of CWD in Native American cultures is warranted.

Acculturation and Variability

While it is important to investigate differences of caregiving experiences between cultures, it is also important to recognize that many studies acknowledge that caregiver experiences and interview responses range greatly also within each collectivistic culture (Goodkind et al., 2015; Locust, 1987; McCallion et al., 1997; Terhune, 2005). Another consideration that influences caregiving perceptions and experiences of disability is the intersecting level of acculturation or bi-cultural identity that they encounter. Diken (2006) attributes the within group variation in methods of treatment to differential influences of acculturation to Western ideology, socio-economic status, and education. Supporting this hypothesis, Maloni et al. (2010) found that younger Bangladeshi mothers in contrast to the elders in the community, favored biomedical treatment approaches more, as they could have been
possibly higher educated and more familiar with Western scientific principles. In another example, Mexican American’s coping style preferences generally varied by generation status, which may be due to the effects of acculturation (Farley et al., 2005; Munet-Vilaro et al., 2002). There is also support for the idea that generation status may influence stigma strength against persons with disabilities, as demonstrated by first-generation Asian Americans who showed higher stigma towards persons with disabilities overall, compared to other U.S. racial groups. They also perceived less differentiation between mental and physical illness regarding the stigma they directed towards those groups (Saetermoe et al., 2001; Weiner, Perry, & Magnusson,1988). Furthermore, in a diverse qualitative investigation of culture and acculturation of families in and outside of the U.S. with developmental disabilities, results showed that those who immigrated to the U.S. were less adherent to traditional cultural beliefs about disability than their counterparts who resided in their home country, with the exception of some cultural values that remained across generations to the U.S. (e.g., family support) (McCallion et al., 1997). Participants explained that they experienced conflicts due to differences in cultural values towards disability within their own family; each family member experienced acculturation differently based on their generation. In addition, some immigrant caregivers noted the apparent internal tension when they seek Western mental health services due to the conflict of choosing between social disadvantages or changing their culture (McCallion et al., 1997). The disparity and range between generations within families was also evident in Goodkind et al.’s (2015) study, wherein Diné (Navajo) youth were largely unaware of traditional healing practices, relying more so on Christian practices, while about half of the parent generation indicated the use of traditional
healing practices, which they used in combination with Christian practices.

Summary

In conclusion, further research is needed to address the needs of multicultural parents of CWD in providing culturally competent and sensitive services, especially given the unique coping and well-being factors based in cultural values and perceptions of disability that are typically not accounted for in research and practice. While prior literature highlights the implications of raising a CWD with both risk and resiliency outcomes, cultural shame and stigmatization placed on the intersection between two minority statuses (ethnic and disability) warrants even greater attention to collectivistic cultures.

Despite this need, there is a great lack of studies that address specific variables of coping and well-being within this population. First, while qualitative studies shed light on the unique and subjective experiences of these parents, more quantitative studies are needed to elucidate the statistical relationships between coping factors and well-being. Second, there is a lack of existing research on ethnic minority or cross-cultural populations in such research samples. Coping research in general primarily include European American participants (Bjorck et al., 2001; Dunahoo et al., 1998; Sampson, 1983; Yeh et al., 2006), which questions the generalizability of Lazarus’ widely used theory to the greater U.S. population. Therefore, prior research may arbitrarily place universal value on individualistic ideas of autonomy, while discounting culturally appropriate coping responses and values of other populations. To add to the etic approaches that may leave out or misrepresent the coping and well-being practices of People of Color groups, emic approaches of examining cultural perspectives may be a helpful step to obtain deeper understanding of various cultures in this regard. In addition, as the majority of
current research in this area represents Asian and Latino immigrants, research on more highly acculturated People of Color communities also warrants further development.

**Hypotheses**

**Research question 1.** Is there a relationship between caregiver stress, including family strain and stigma, and well-being in parents of CWD?

There will be a significant negative correlation between caregiver stress and well-being in parents of CWD, wherein increased family strain and experienced stigma will be associated with lower well-being scores. This hypothesis is based in McCubbin and Patterson’s (1983) Double ABCX Model, which suggests that the additive stressors (i.e., Pile-up of demands) on the family can affect the family’s adaptation. This hypothesis is also based in previous literature, suggesting that the pile-up of stress, including child behavior problems and economic strain while raising a CWD, results in decreased mental health and well-being outcomes (Baker et al., 2005; Breslau & Davis, 1986; Kersh et al., 2006; Llyod and Hastings, 2009; Mahoney et al., 1992; Olsson & Hwang, 2008), and that a child’s functioning, associated with the experience of burden, affects parents’ well-being over time (Early, Gregoire, & McDonald, 2002).

**Research question 2.** Does coping mediate the relationship between caregiver stress and well-being?

Coping (M) will be a partial mediator in the relationship between caregiver stress (Pile-up; X) and well-being (Y) outcomes. Figure 1 depicts the relationships between the variables predicted in the mediator model. Amongst parents who have children with disabilities, positive adjustment/well-being has been evidenced (Baker et al., 2005; Kersh et al., 2006; Lewis et al., 2006; Olsson & Hwang, 2008). The demonstration of positive adjustment in parents who
undergo caregiver stress may suggest the possibility that stress does not directly cause poor well-being outcomes in parents, but that there may be indirect variables within this relationship that exist. The Double ABCX Model (McCubbin & Patterson, 1983) suggests that coping mediates the relationship between stressors and adjustment, wherein the effectiveness of coping, amongst other familial factors, can determine whether or not the family restores its adjustment and harmony. These ideas are based in previous literature showing that most families adapt well to crises and that they do so by changing their ways of functioning to adapt to such changes in demands (McCubbin, Dahl, Lester, & Ross, 1975). In addition, Lazarus and Folkman’s coping and stress model also views coping as an important mediating variable between and individuals’ stress and resulting emotions and outcomes (Folkman & Lazarus, 1988a; Folkman et al., 1986). For example, caregiving literature for family members with Alzheimer’s disease demonstrated that coping is a mediating variable between stress and adjustment outcomes (Haley et al., 1996; Morano, 2003; Pruchno & Resch, 1989). It is also predicted that whether or not there are significant mediating effects, the total effects may also be partially due to factors that are not accounted for in these analyses that have also been shown to affect well-being outcomes (e.g., Family Resources, Stressor Appraisal; Folkman et al., 1986; McCubbin, Thompson, & McCubbin, 1996).
Figure 1. Diagram depicts the predicted mediator model of the effects of Pile-up and Coping on Well-Being.

**Research question 3.** Does racial group identification (European American/People of Color) predict caregiver coping?

Since there has been no prior research applying both etic and emic approaches of coping with this population, this is an exploratory research question/hypothesis. However, a tentative hypothesis may be that there are differences in cultural values between People of Color and European Americans that influence preferences towards coping behaviors. More specifically, People of Color may rely more heavily on Collectivistic Coping strategies. This hypothesis is based on multicultural and cross-cultural literature that show People of Color cultures’ emphasis on family and social support (Cohen et al., 2014; Cohen et al., 2015; Ha et al., 2011; McAdoo, 1982; Sage & Jegatheesan, 2010; Zea et al., 1994), along with forbearance in enduring problems with non-disclosure (Chang, 2015; Choi & Wynne, 2000; Inman & Yeh, 2007; Matthews et al., 2006; Tweed et al., 2004), and fatalism, with emphasis on spirituality and having higher meaning for the child’s disability (Daudji et al., 2011; Diken, 2006; Matthews et al., 2006; Rogers-Dulan & Blacher, 1995; Sheets et al., 2012; Skinner et al., 1999; Terhune, 2005; Zea et al., 1994). The predictive value of racial identification on use of Engagement or Disengagement may not be
significant (i.e., People of Color and European Americans will have similar endorsement of these coping styles); however, because of the inconsistency in research findings regarding active versus passive coping among various racial groups, this research question aims to be exploratory in nature.
Participants and Recruitment

Participants were recruited from community programs/organizations that serviced families of CWDs, parent support groups, private pre-schools or elementary schools, national email listserves, Facebook support groups and disability pages, and professional networks. Recruitment was conducted across the U.S., but was mainly concentrated in Washington and Hawaii, and in highly populated, culturally diverse major cities. The researcher informed the authorities and/or coordinators of these programs about the current study, and asked them for their consent to recruit participants of interest (parents/caregivers of CWDs) by email or mailing them an invitation and flyer to forward, hand out, or post on their website to the target population. Because information about this study was distributed through social/online media forums or pages (45+) and groups (40+), disability organizations (40+), and national email lists (5+) across the U.S., the amount of potential participants reached is indeterminable, and likely beyond 5,000. Participants were also recruited through the snowball method, in which participants were invited to ask other potential participants to join the study. The criteria for eligibility in this study are that the participant is: (a) 18 years-old; and is (b) a guardian or caregiver of a child (0-21 years old) with an unspecified or diagnosed disability and/or is receiving special needs services.

Among these various means of recruitment, the breakdown of the participant sample was: 43.3% Facebook/social media, 25.9% Community organization/program/group, 19.9% Other,
8.8% Family/friend referral, and 2.1% School system. The majority of those that identified “Other” as their means of being recruited indicated that they heard about the study from a listserv. From the overall sample people who took any part of the survey \((n=473)\), 386 participants were retained for the analyses.

**Demographics**

The distribution of racial identification was: 69.2% European American \((n=267)\), 11.4% Asian/Pacific Islander \((n=44)\), 9.1% Multiracial \((n=35)\), 6.2% Latina/o \((n=24)\), and 4.1% Black/African American \((n=16)\). Any participant who identified as Asian/Pacific Islander, Latina/o, or Black/African American, and/or Native American was considered People of Color. The sample was composed of 69.2% European Americans \((n=267)\) and 30.8% People of Color \((n=119)\). Sample characteristics for are listed in Table 1. Missing data were not included in these percentages.

**Table 1**

*Sample Characteristics*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Overall ((n=386))</th>
<th>European American ((n=267))</th>
<th>People of Color ((n=119))</th>
</tr>
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<tbody>
<tr>
<td><strong>Caregiver</strong></td>
<td></td>
<td></td>
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<tr>
<td>Gender</td>
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<tr>
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<td>93.8%</td>
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<td>Mean Age in Years (SD)</td>
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<td>41.7 (7.9)</td>
<td>42.9 (8.2)</td>
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<td>1(^{st})</td>
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<td>27.7%</td>
</tr>
<tr>
<td>2(^{nd})</td>
<td>8.8%</td>
<td>5.2%</td>
<td>16.8%</td>
</tr>
<tr>
<td>3(^{rd})</td>
<td>13.0%</td>
<td>12.7%</td>
<td>13.4%</td>
</tr>
<tr>
<td>4(^{th}) and above</td>
<td>45.3%</td>
<td>56.2%</td>
<td>21.0%</td>
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</table>
## Measures

### Family Strains

The *Family Strains Index* (McCubbin & Patterson, 1982) is a part of a set of measures called the FIRA-G (Family Index of Regenerativity and Adaptation-General), designed to assess the general impacts of stressful life events that a family may encounter which cause vulnerability and a need for change or adaptation (i.e., Pile-up of stressors) in the Resiliency Model of Family Stress, Adjustment and Adaptation. This measure is a 10-item self-report questionnaire in which respondents are asked to decide if they have experienced various family stressors (e.g., “Increase in conflict among children in the family”) in the past year by selecting “Yes” or “No.” Corresponding weights (defined by McCubbin & Patterson, 1982) of each endorsed item are

<table>
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<tr>
<th>Highest Education</th>
<th>Not Applicable/Unknown</th>
<th>≤High School/GED</th>
<th>Trade School</th>
<th>College Degree</th>
<th>Graduate Degree</th>
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<tr>
<td></td>
<td>18.9%</td>
<td>18.7%</td>
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<tr>
<td></td>
<td>11.1%</td>
<td>10.1%</td>
<td>13.4%</td>
<td>43.3%</td>
<td>43.8%</td>
</tr>
<tr>
<td></td>
<td>30.8%</td>
<td>32.2%</td>
<td>27.7%</td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Annual Household Income</th>
<th>&lt;$25,000</th>
<th>$25,000-$49,999</th>
<th>$50,000-$74,999</th>
<th>$75,000-$99,999</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9.3%</td>
<td>14.8%</td>
<td>15.8%</td>
<td>17.4%</td>
<td>40.4%</td>
</tr>
<tr>
<td></td>
<td>7.5%</td>
<td>16.1%</td>
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<td>41.2%</td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Child</th>
<th>Gender</th>
<th>Condition</th>
<th>Mean Age in Years (SD)</th>
<th>Mean Years Since Diagnosis, (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Multiple</td>
<td>9.3 (5.2)</td>
<td>6.3 (4.9)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>Autism/ASD</td>
<td>9.1 (5.1)</td>
<td>6.3 (4.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other Single Condition</td>
<td>9.4 (5.2)</td>
<td>6.4 (4.8)</td>
</tr>
</tbody>
</table>
added together. This sum is then divided by 10 to obtain an overall Family Strains Score. The Cronbach’s alpha from the scale’s original study was .69 (McCubbin & Patterson, 1982). The Cronbach’s alpha for Family Strains in this study was .74.

Stigma

The Inventory of Stigmatizing Experiences (Stuart, Miley, & Koller, 2005) is a self-report questionnaire used to assess a parent’s or relative’s perception of his/her experiences with stigma related to a family member’s serious mental illness. For the purposes of this study, “mental illness” was replaced with “disability” and “relative” was replaced with “child” in the items of the questionnaire. This inventory was designed without specific caregivers, conditions, or contexts for its intended use, but as a way to promote mental illness stigma reduction by providing a means to assess and evaluate it. This inventory contains two scales. The Stigma Experiences Scale (7 items) measures the frequency and prevalence of stigma experiences, and the Stigma Impact Scale (7 items) measures the psychological and social impact of such experiences on the respondent. The Family versions of each of these scales were used to assess the caregiver’s perspective. The first 4 items (e.g., “Do you think that people think less of those with a mental illness?”) of the Stigma Experiences Scale are rated by participants on a 5-point rating scale from “Never” to “Always.” The following 3 items (e.g., “Has stigma affected your family’s ability to make or keep friends?”) are rated by participants using the following choices: “Yes,” “No,” and “Unsure.” Responses are sorted into binary categories with 1 point assigned to “Often” and “Always” responses in the first 4 items and “Yes” responses in the last 3 items. 0 points are assigned to “Never,” “Rarely,” or “Sometimes” responses in the first 4 items and “No” and “Unsure” responses in the last 3 items. Scores are then summed with a 0-7 point total score.
range. In this study, the Cronbach’s alpha for the Stigma Experiences Scale was .76, which was equal to the reliability reported in the scale’s original study (Stuart et al., 2005). The Stigma Impact Scale asks participants to rate how much stigma has negatively affected them or their family as a whole on a scale of 0 to 10, with 0 indicating no impact and 10 indicating the highest amount of impact. Responses are summed into a 0-70 total score, with higher scores indicating a greater impact of stigma. In this study, the Cronbach’s alpha coefficient for the Stigma Impact Scale was .93, which was equal to the reliability reported in the scale’s original study (Stuart et al., 2005).

**Individualistic Coping**

Coping from an individualistic perspective was assessed using an adapted version of the Coping Strategies Inventory-Short Form 32 (CSI-S; Tobin, 1995). This questionnaire was originally adapted from the *Ways of Coping Questionnaire* (Folkman & Lazarus, 1988b). The CSI-S is a 32-item self-report questionnaire that assesses the specific situations that people face and how they cope. The instructions to this measure were adapted such that participants were asked to think about a specific stressor in the past month related to managing their child’s disability. Participants rate each coping item on a scale of 1 to 5 (“Not at all” to “Very Much”) based on the extent to which they used each strategy to handle this specific stressor. Coping approaches were captured by tertiary subscales of *Engagement* and *Disengagement*. *Engagement* is classified by a person’s ongoing and active efforts to manage the relationship between oneself and his/her problem or environment, including taking direct action to change one’s situation or perspective and/or seeking ways to soothe distress. On the other hand, *Disengagement* is classified by withdrawal from the person’s stressful environment or problem(s), including the
avoidance of feelings and thoughts associated with the source of stress and a lack of effort to enact change. Scores are calculated by adding the item ratings in each subscale. Higher scores indicate a greater use of the coping strategy. The Cronbach’s alphas reported from the scale’s original study for Engagement and Disengagement were .90 and .89, respectively. In this study, the Cronbach’s alpha coefficients for the Engagement and Disengagement subscales were .86 and .83, respectively.

**Collectivistic Coping**

Collectivistic coping was measured using the *Collectivistic Coping Scale* (CCS; Yeh, Chang, Arora, Kim, & Xin, 2003), which is a 35-item self-report questionnaire. This scale was designed to measure coping strategies of persons who have interdependent or collectivistic self-construals in dealing with a specific stressor. However, it is recommended that researchers examine both individualistic and collectivistic coping strategies alongside each other, as persons from both individualistic and collectivistic orientations can endorse either coping approach independently from one another based on the situation (Coon & Kemmelmeier, 2001). This scale consists of 7 factors, including: *Respect for Authority* (seeking support from elders or mentors in the community), *Forbearance* (refraining from sharing problems), *Social Activity* (using social networks), *Intracultural Coping* (seeking support through racially similar individuals), *Relational Universality* (seeking relationships from those who share similar experiences), *Fatalism* (perceiving one’s problems as predetermined), and *Family Support* (seeking help from family members). The instructions were adapted such that participants were asked to respond to a problem they encountered within the past 6 months related to their child’s disability. Participants rate the extent to which they used each strategy (e.g., “Sought out a member of my
racial/cultural group) to deal with this problem based on a 7-point rating scale ranging from “Not Used” to “Used a Great Deal.” Scores are calculated by adding the item ratings in each subscale. Higher scores indicate a greater use of the coping strategy. The Cronbach’s alpha coefficients for the 7 factors ranged from .80 to .93 in the scale’s original study (Yeh et al., 2003). The Cronbach’s alpha coefficients for the 7 factors ranged from .73 to .94 in this study.

Well-Being

The Satisfaction With Life Scale (SWLS; Diener et al., 1985) was used to assess subjective well-being or global life satisfaction and is intended for use in all age groups. This scale is a 5-item self-report questionnaire in which participants respond to five statements about their life (e.g., “In most ways, my life is close to my ideal”) based on a 7-point rating scale, ranging from “Strongly Disagree” to “Strongly Agree.” The total score is calculated by adding the ratings for each item, with higher scores indicating a greater subjective well-being. The Cronbach’s alpha coefficients for the SWLS in this study and the scale’s original study were .88 and .87, respectively (Diener et al., 1985).

The Relational Well-Being II Scale (RWB II; McCubbin et al., 2013) was used to assess well-being from an alternative culturally-sensitive, indigenous perspective. Well-being from this approach extends the former well-being theories based in Western-European culture to a person’s connection to social networks, nature, culture, resources, and spirituality. The population from which this scale was developed and normed was indigenous communities in Hawaii. This scale is a 14-item questionnaire consisting of 6 factors: Community Well-Being, Culture Well-Being, Financial Well-Being, Family Well-Being, Health Care Well-Being, and Resilience. However, only the total score was used in this study. Participants are asked to rate
how much they engage in each behavior (e.g., “I was actively involved in community activities”) in the past 12 months on a 4-point rating scale, ranging from “None of the time” to “All of the time.” The total score is calculated by adding the item ratings together. Higher scores indicate a greater well-being. The Cronbach’s alpha coefficients reported for individual factors of the original study ranged from .62-.76 (McCubbin et al., 2013). In this study, the Cronbach’s alpha coefficient for the total Relational Well-Being Scale was .71.

The *Scales of Psychological Well-Being* (SPWB; Ryff, 1989) is a self-report questionnaire used to measure psychological functioning based in humanistic theory. While there are 6 subscales altogether, the Personal Growth (9 items) and the Purpose in Life (9 items) subscales were selected to be used in this study in particular, given the salience of a caregiver’s process of change in their worldviews about openness to experience and reasoning of the disability and its situational challenges (King et al., 2009). Personal Growth reflects one’s perception of his/her development and improvement of him/herself though time, while Purpose in Life assesses for one’s sense of meaning in and goals/objectives of living. Participants respond to each item (e.g., “I have a sense of direction and purpose in life”) based on a 6-point rating scale, ranging from “Strongly Disagree” to “Strongly Agree.” Scores are calculated by adding the ratings of the items in each subscale, wherein 6 items are reverse coded. Higher scores indicate a greater well-being. The Cronbach’s alpha coefficients reported for the Personal Growth and Purpose in Life subscales in the original study were .85 and .88, respectively (Ryff, 1989). In this study, the Cronbach’s alpha coefficients for the Personal Growth and Purpose in Life subscales were .78 and .86, respectively.
Procedure

The researcher sent an email announcement/flyers/letters or Facebook post (upon receiving permission) about the study to forward to targeted participants, inviting them to participate in the study. The informed consent explained the confidentiality of the information they provide, and that the results may be used for a presentation or publication, with aggregate findings. The consent form provided contact information for the researchers and community resources for further services in case they were needed. They were directed to a Qualtrics website, which contained an online survey that took approximately 20 minutes to complete. The survey was presented in a semi-random order, with the demographic items appearing first for all participants, and the following pages of questionnaires presented in random order:

- Family Strains Index, Inventory of Stigmatizing Experiences
- Coping Strategies Inventory
- Collectivistic Coping Scale
- Satisfaction With Life Scale, Relational Well-Being Scale
- Ryff’s Scales of Psychological Well-Being (Personal Growth and Purpose in Life scales)

After participants were done, they were directed to a separate survey page, in which they could voluntarily provide their contact information (i.e., email address) to participate in a raffle for one of 3 $100 Amazon gift certificates. Participation in the prize raffle was not required.

Methods of Analyses

Analysis Plan

Path analyses using structural equation modeling were used to test exploratory models, based in the Double ABCX Model (McCubbin & Patterson, 1983), regarding the relationship
between family stressors (i.e., pile-up), coping, and overall well-being (i.e., adaptation). The maximum likelihood (ML) estimation method was used to determine the standardized parameter estimates for the model. Model fit was determined by the recommended criteria of Hu and Bentler (1999), such that the Root Mean Square Error of Approximation (RMSEA) is equal to/less than .05, the Standardized Root Mean Square Residual (SRMR) is equal to/less than .09, the Comparative Fit Index (CFI) is equal to/greater than .95, and the Non-normed Fit Index (NNFI) is equal to/greater than .95. In addition, a chi-square statistic with significance values greater than .05 will be deemed as having adequate fit. In all modeling interpretation, standardized regression estimates were deemed to be “practically” significant or meaningful based on the recommended measures for strength of association type effect sizes in the social sciences: low = .2; moderate = .5; strong = .8 (Ferguson, 2009). In using these guidelines, effect size values were rounded to the nearest tenth.

**Exploratory Models**

The initial exploratory models were geared towards exploring how demographic variables, specific stressor variables, and specific coping strategies related to each other as they influenced each of the 4 well-being outcomes. Due to the exploratory nature of the analyses, model trimming and model respecifications/modifications were tested based on empirical data (i.e., modification indices; Sörbom, 1989) and theoretical bases.

**Variables.** Because there has not been any prior literature that have examined the combination of factors in this study with caregivers of CWD, especially with the addition of stigma experiences/impact and collectivistic coping strategies, an exploratory approach was taken to find the most parsimonious model for each dependent variable to best explain the
phenomenon of stress, coping, and well-being. All variables were entered in the first tested model. More specifically, only demographic variables that had a significant bivariate correlation ($p < .05$) with the DV at hand were included. In addition, the Stigma variable represented the sum of Stigma Experiences and Stigma Impact, because of the significant correlation ($r = .649, p < .001$) between them, which was used throughout the 4 exploratory SEM analyses. All coping strategies from the CSI (Engagement, Disengagement; Tobin, 1995) and the CCS (Respect for Authority, Forbearance, Social Activity, Intracultural Coping, Relational Universality, Family Support, and Fatalism; Yeh et al., 2003) were included in the initially tested models.

**Model respecifications.** All coping variables were entered and tested in the initial model. Coping factor disturbances were allowed to freely covary based on the recommendation of Preacher and Hayes (2008) regarding multiple mediator models. This practice will account for contributors of covariation among mediators that were not included in the model (Preacher & Hayes, 2008). Hypothesized unmodeled factors that may contribute to the residual covariances may include: (a) impression management, wherein participants may have been influenced to respond based on what they felt might be socially acceptable; and (b) response style, due to the repetitive nature and length of the coping questionnaires. Regression paths were tested from all exogenous variables to all endogenous variables, and from all Coping variables to the dependent variable (i.e., well-being). Coping variables that did not significantly predict the dependent variable were trimmed one-by-one. Exogenous predictor variables (Demographic variables, Stigma, Family Strains) that did not significantly predict any coping or well-being variable were trimmed one-by-one. Remaining exogenous variables that were significantly correlated with
each other were then allowed to freely covary. Lastly, regression paths that were not significant ($p > .05$) were also trimmed one-by-one.

**Mediation analyses.** Mediation analyses were conducted using the bias-corrected bootstrap method, as recommended by MacKinnon, Lockwood, and Williams (2004) and Preacher and Hayes (2004), with a 95% confidence interval and 2000 resampling draws. Former mediation approaches ascertained a mediation by the presence of: (a) a significant direct effect from the predictor variable (demographic or stressor) to the dependent variable (well-being measure); (b) a significant path from the predictor to the mediator; (c) a significant path from the mediator to the dependent variable, with the independent variable also predicting the dependent variable; and (d) the coefficient from the independent to dependent variable being larger than the coefficient from the independent to dependent variable with the mediator included in the model (Baron & Kenny, 1986). However, recent scholars state that only conditions of b and c are necessary for a significant mediation to exist, and that there are in fact many cases in which the regression between the independent and dependent variable may not be significant (MacKinnon, Fairchild, & Fritz, 2007). An insignificant relationship between X and Y is often present in models with more than one mediator with mediation processes that are opposite in direction, and/or in inconsistent mediation models, wherein the signs between the mediating and direct effects are opposite (MacKinnon, Krull, & Lockwood, 2000; MacKinnon et al., 2007).

In addition, a partial mediation was determined if the direct effect with the mediator included in the model was still significant (MacKinnon et al., 2007) and/or had a non-zero coefficient.

Mediation relationships were tested with significant coping variables in the relationships between predictor variables and well-being outcomes. Completely standardized effects (i.e.
standardized regression estimates of the indirect effect) were used to determine the significance and effect of the mediation model. To control for a Type I error given the number of mediation analyses conducted, mediations were deemed significant if the standardized indirect effect had a $p$-value of < .01. Hayes (2013) acknowledged that research is still evolving in determining the best practices of representing effect size in mediation analyses, and that attributing ranges as to what is deemed “practically” significant is arbitrary and subjective, as the meaning of what is considered a small or large effect may vary based on context. While first acknowledging that there is unavoidable subjectivity in labeling effect sizes, some authors suggested using $r^2$ effect size indicators as an analogous guideline to apply to mediation effect sizes, being .01 for low, .09 for moderate, and .25 for strong (Kenny, 2015; Preacher & Kelley, 2011).

**Overall Model**

The Overall Model was based on a portion of the Double ABCX Model (McCubbin & Patterson, 1983), hypothesizing that Coping mediates the relationship between Pile-up and Adaptation (i.e., Well-being).

**Variables.** All predictor variables were standardized prior to being combined to make broader variables fitting to the Double ABCX Model (McCubbin & Patterson, 1983). Pile-up represented the sum of Stigma (Experiences and Impact) and Family Strains. Collectivistic Coping represented the sum of significant Coping variables from the exploratory SEM analyses, including Respect for Authority, Relational Universality, Fatalism, and Forbearance. Individualistic Coping was represented by its individual factors of Engagement and Disengagement. Because these two constructs were proposed to impact Well-Being in opposing ways, it did not make statistical sense to combine them into one Individualistic Coping variable.
The adaption construct of the Double ABCX Model (McCubbin & Patterson, 1983) was represented by Well-Being, which was the sum of the specific well-being factors, Satisfaction with Life (SWL), Relational Well-Being (RWB), Personal Growth (PG), and Purpose in Life (PL). Thus, the outcome variable is comprehensively composed of hedonic, psychological, and relational well-being.

**Trimming.** Initial regression paths that were tested in the Overall Model include paths from Pile-up and significant demographic variables (Parent Age, Income, Racial Identification) onto all endogenous variables. Regression paths were also tested from the 3 coping variables onto Well-Being. Regression paths and demographic variables that were not significant were trimmed to obtain the most parsimonious model. The handling of model respecifications, covariances, mediation testing, and determining model fit were identical to the aforementioned SEM analyses.
CHAPTER FOUR

RESULTS

IBM SPSS 23 was used for all descriptive and inferential analyses in this study. In addition, SEM and mediation analyses were conducted using IBM SPSS AMOS (Version 23).

Handling Outliers

Before missing data were replaced, outlying data points were deleted and cases deemed ineligible for the study were excluded. Mahalanobis distances were used in AMOS to determine any outliers in the cases used for SEM analyses. Results in all 4 DV models found that the lowest \( p \)-value for a case being an outlier was .006 for SWL and .004 for PL. These values are all greater than the cut off for the conservative \( p < .001 \) boundary per recommendation of Tabachnick and Fidell (2013). On the other hand, RWB had 1 case and PG had 5 cases less than .001, indicating likelihood of an outlier. Since there was a minimal amount of those that meet criteria for an outlier in all cases across DV models, all data were retained in the analyses.

Demographic data that were formatted as open responses were also screened for reasonability and potential carelessness. One outlier for number in the household of “32” was deleted and an outlier of “1983” for number of years since diagnosis was deleted. In addition, 9 ineligible participants who identified as international were excluded from further analyses. According to the literature, persons who live in countries outside of the U.S. show differences in coping and perceptions of disability compared to people from these countries who immigrate to the U.S., likely due to the influence of acculturation and bi-cultural processes (McCallion et al., 1997; Parette et al., 2004). Thus, because this study focused on exploring coping diversity within the U.S., it did not make theoretical sense to include international participants in this study.
Categorical variables were also cleaned to aid the efficiency and effectiveness of analyses, according to the distribution of cases in each category. Sparsely represented categories were combined with conceptually similar (for nominal) or adjacent (for ordinal) categories in such variables. When categories with 1 or 2 cases were not conceptually able to be grouped with other categories, they were excluded from the analyses. Categories with 0 cases were dropped altogether.

**Handling Missing Data**

Because the survey was about a 20-minute online survey on multiple pages, there was a substantial amount of missing data, wherein participants dropped out after different points of the survey. Among the 473 participants that entered and participated in at least some of the survey, 54.8% had at least one missing data item. There were also 28.57% missing data points in the entire data set. Data was missing from 133 out of 134 variables overall, ranging from 35.7% (CSI items) to .4% missing (4 demographic items: Caregiver, People of Color, Parent Education, Child Gender) for each variable.

In addition, a visual graph for missing data patterns was assessed, confirming that the missing data were arbitrarily distributed, and that they appeared to be more commonly missing in chunks at a time (i.e., whole questionnaires as opposed to single items). In addition, by examining the descriptive frequencies of missing data by variable, it appeared that the longer coping questionnaires (i.e., CSI, CCS) had the highest levels of missing data, with intermediate measures in length having the next highest levels of missing data (e.g., Ryff’s PSWB, RWB), and the demographic variables having the least amount of missing data. The most frequent pattern of data was with participants having all data completed (68% of cases), with the second
most frequent pattern (18% of cases) being data completed only through the last demographic item. Other patterns of missing data were dispersed evenly at 5% of cases or lower. One factor contributing to this pattern of drop out may be fatigue, especially considering the elevated drop out after encountering higher item volume questionnaires. Factors contributing to an arbitrary, blocked pattern of missing data after the demographic items may be due to the nature of the presentation of the questionnaires, which were shown randomly on separate pages after the demographics, which was always presented first.

Data from cases that were entirely missing past the demographics information (18% of total) were excluded from further analyses on the basis that they did not participate in the actual questionnaires of research interest. T-test and Chi-square comparisons were conducted on demographic variables to indicate any differences between the group of participants that were retained or excluded, finding no significant results on the following factors: caregiver relationship, caregiver marital status, racial identification, generation to the U.S., parent education, and household income.

The following results are based on missing data analyses with cleaned data (n=386), after cases were excluded based on missing data past demographics and ineligible international participants, and categorical variables were cleaned. Little’s Missing Completely at Random (MCAR) analysis on an item level was deemed insignificant, indicating that the data is MCAR ($\chi^2 = 7837.997$, $df = 7859$, $p = 0.564$). Results showed that there were 136/140 variables with missing data, 45.08% of cases with any missing data, and 15.45% of missing data points overall. Variables were missing data with percentages ranging from 22.3% (CSI items) to no missing data (in 4 demographic variables). The pattern of the distribution of missing data among
variables was comparable to the pattern seen before missing past demographic data and international cases were excluded, with Coping items having the most missing data, followed by other questionnaires, and then demographic items having the least missing data. About 75% of cases contained complete data, being the most common pattern, and then the following patterns of missing data each represented 5% of cases or less. Patterns again, appeared in an arbitrary fashion.

Due to data being MCAR, there was justification to use Expectation Maximization (EM) to replace missing data points. Data were replaced using EM by for individual items for each subscale at a time. Additional analyses were run to compare multiple imputation and maximum likelihood methodologies for handling missing data, all of which yielded the same, if not very similar interpretive results.

**Assessing for Normality**

Skewness and Kurtosis were evaluated for the imputed data of the continuous variables. Skewness ranged from -.918 (Personal Growth) to 1.244 (Intracultural Coping) and Kurtosis ranged from -.923 (Stigma Experiences) to .940 (Personal Growth) between all factors. According to West, Finch, and Curran’s (1995) cut off of absolute skew value of > 2 and absolute kurtosis value of > 7, assumptions of normality were adequately met. In addition, with reasonably large samples (100-200+ cases), Tabachnick and Fidell (2013) suggested that the impacts of the distance of skewness and kurtosis from zero are minimized.
Descriptive Statistics

Table 2

Descriptive Statistics of Composite Scores

<table>
<thead>
<tr>
<th></th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>SD</th>
<th>Skewness Statistic</th>
<th>Std. Error</th>
<th>Kurtosis Statistic</th>
<th>Std. Error</th>
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<tbody>
<tr>
<td>Family Strains</td>
<td>0.00</td>
<td>41.80</td>
<td>17.99</td>
<td>11.04</td>
<td>0.38</td>
<td>0.12</td>
<td>-0.77</td>
<td>0.25</td>
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<td>Stigma Experiences</td>
<td>0.00</td>
<td>7.00</td>
<td>2.75</td>
<td>2.13</td>
<td>0.53</td>
<td>0.12</td>
<td>-0.92</td>
<td>0.25</td>
</tr>
<tr>
<td>Stigma Impact</td>
<td>0.00</td>
<td>70.00</td>
<td>26.92</td>
<td>17.43</td>
<td>0.28</td>
<td>0.12</td>
<td>-0.74</td>
<td>0.25</td>
</tr>
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<td>Engagement</td>
<td>19.00</td>
<td>75.00</td>
<td>49.58</td>
<td>10.19</td>
<td>-0.13</td>
<td>0.12</td>
<td>0.21</td>
<td>0.25</td>
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<td>Disengagement</td>
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<td>0.61</td>
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<td>0.25</td>
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<td>Respect for Authority</td>
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<td>15.06</td>
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<td>0.12</td>
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<td>0.25</td>
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<td>Forbearance</td>
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<td>Intracultural Coping</td>
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<td>35.00</td>
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<td>7.85</td>
<td>1.24</td>
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SEM Results

Race was coded as a binary variable (0=European American; 1=People of Color).

Regression coefficients for the initial model, which included all possible paths between the significantly correlated demographic variables, stress variables, coping variables, and well-being outcome variable are shown in Tables 3 (SWL), 7 (RWB), 11 (PG), 15 (PL), and 19 (Overall).

From these analyses, insignificant variables and regression paths were trimmed for model parsimony to create the final models. The regression coefficients from the final SWL, RWB, PG,
PL, and Overall models are shown in Table 4, 8, 12, 16, and 20, respectively. The SEM path diagrams with standardized regression coefficients are shown in Figures 2-6.

Path Analyses for Satisfaction with Life (SWL)

Table 3

Maximum Likelihood Parameter Estimates for Initial SWL Model

<table>
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<tr>
<th></th>
<th>Est.</th>
<th>Stand. Est.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>p</th>
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Table 4

**Maximum Likelihood Parameter Estimates for Final SWL Model**

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<th>Est.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>p</th>
</tr>
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Table 5

**Covariances for Final SWL Model**

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Table 6

Fit Criteria for SWL Model Respecifications

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<th>CFI</th>
<th>NNFI</th>
<th>RMSEA/90% CI</th>
<th>SRMR</th>
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Stigma was significantly covaried with Family Strains, while Race and Income were not significantly covaried with any other exogenous variable. Fatalism was shown to be positively related to, or elicited more by People of Color (Racial Identification), families with lower income, and by highly strained family situations (Family Strains). In particular, the positive relationship between being a Person of Color on use of Fatalism was practically significant (low effect size). Higher experienced stigma was related to lower use of Engagement and decreased SWL. Higher family strain also predicted decreased SWL, while higher income predicted increased SWL. The coping styles that significantly and positively predicted SWL were Engagement, Relational Universality, and Fatalism. Among the aforementioned effects of the
SWL Model, the negative effect of Stigma and positive effect of Income and Relational Universality onto SWL had practically significant, low effect sizes; whereas the other effects onto SWL did not meet criteria for practical significance. The disturbances of Relational Universality, Engagement, and Fatalism were covaried to account for social desirability and response bias. The final model showed adequate fit \( \chi^2 (14) = 20.091, p = .127, \text{CFI} = .976, \text{NNFI} = .952, \text{RMSEA} = .034 \) (90% confidence interval = .000 - .064), and \( \text{SRMR} = .039 \).

All of the statistically significant mediation effects for this model were deemed practically significant with a low effect size. There were significant mediation effects, such that Engagement partially mediated the relationship between Stigma and SWL (Standardized direct effect = -.238, \( p < .001 \); Standardized indirect effect = -.017, \( p = .008 \); Standardized total effect = -.249, \( p < .001 \)). In other words, the negative direct effect of Stigma onto SWL is partially accounted for by the indirect effect such that higher Stigma predicts lower use of Engagement, which thereby predicts decreased SWL. Secondly, Fatalism was an inconsistent partial mediator in the relationship between Income and SWL (Standardized direct effect = .186, \( p < .001 \); Standardized indirect effect = -.021, \( p = .005 \); Standardized total effect = .153, \( p = .001 \)). While higher income is typically related to higher SWL (i.e., positive direct effect), this effect is inconsistent with the co-occurring, negative indirect effect such that higher income also predicts lower use of Fatalism, which thereby predicts decreased SWL. The mediation effect of Fatalism on the relationship between Family Strains and SWL was not significant (Standardized indirect effect = .012, \( p = .017 \)).
Figure 2. SEM path diagram for Satisfaction with Life (SWL) with standardized ML regression coefficients

Path Analyses for Relational Well-Being (RWB)

Table 7

Maximum Likelihood Parameter Estimates for Initial RWB Model

<table>
<thead>
<tr>
<th></th>
<th>Est.</th>
<th>Stand.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>p</th>
</tr>
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<tbody>
<tr>
<td>Engagement ← Mar. Status</td>
<td>2.005</td>
<td>.077</td>
<td>1.289</td>
<td>1.556</td>
<td>.120</td>
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<tr>
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<td>1.133</td>
<td>-1.064</td>
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<tr>
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<td>.939</td>
<td>-1.077</td>
<td>.281</td>
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<td>.842</td>
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<td>1.028</td>
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<tr>
<td>Fatalism ← Mar. Status</td>
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<td>.072</td>
<td>.741</td>
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<td>.500</td>
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<td>-------</td>
<td>------</td>
</tr>
<tr>
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<td>0.000</td>
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<td>.996</td>
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<td>R. Authority ← Parent Edu</td>
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<td>0.047</td>
<td>0.393</td>
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<td>S. Activity ← Parent Edu</td>
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<td>0.326</td>
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<td>Relational U. ← Parent Edu</td>
<td>0.135</td>
<td>0.016</td>
<td>0.398</td>
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<td>Fam. Support ← Income</td>
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<td>0.094</td>
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<td>-1.254</td>
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<td>-.506</td>
<td>.613</td>
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<td>.002</td>
<td>.700</td>
<td>.484</td>
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<td>.002</td>
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Table 8

Maximum Likelihood Parameter Estimates for Final RWB Model
Table 9

*Covariances for Final RWB Model*

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<th>S.E.</th>
<th>C.R.</th>
<th>r</th>
<th>p</th>
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<td>Fam. Strains ↔ Stigma</td>
<td>17.304</td>
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<td>7.971</td>
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<td>&lt;.001</td>
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<td>e1 ↔ e2</td>
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<td>2.215</td>
<td>4.340</td>
<td>.227</td>
<td>&lt;.001</td>
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Table 10

*Fit Criteria for RWB Model Respecifications*

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<tr>
<th>Step</th>
<th>$x^2$ goodness of fit</th>
<th>CFI</th>
<th>NNFI</th>
<th>RMSEA/ [90% CI]</th>
<th>SRMR</th>
</tr>
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<tbody>
<tr>
<td>2. Trim non-significant coping variables</td>
<td>292.945 ($df = 21$)</td>
<td>.427</td>
<td>- .227</td>
<td>.184 [.166, .203]</td>
<td>.124</td>
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<tr>
<td>3. Trim non-significant demographic variables</td>
<td>93.312 ($df = 6$)</td>
<td>.694</td>
<td>- .070</td>
<td>.195 [.161, .231]</td>
<td>.099</td>
</tr>
<tr>
<td>4. Covary significantly correlated exogenous variables</td>
<td>8.371 ($df = 5$)</td>
<td>.988</td>
<td>.950</td>
<td>.042 [.000, .090]</td>
<td>.031</td>
</tr>
<tr>
<td>5. Trim non-significant regression paths</td>
<td>18.285 ($df = 12$)</td>
<td>.978</td>
<td>.961</td>
<td>.037 [.000, .069]</td>
<td>.051</td>
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</table>

Stigma was significantly covaried with Family Strains, while Race and Income were not significantly covaried with any other exogenous variable. Family Strains negatively predicted RWB, which was both statistically and practically significant, having a low effect size. Higher Stigma related to higher use of Forbearance, and higher use of Forbearance related to decreased RWB. Of these two sequential effects, Stigma’s positive effect on Forbearance had both
statistical and (low) practical significance. No significant direct relationship between Stigma and RWB existed. Higher income predicted higher RWB and lower use of Fatalism. Out of these two statistically significant relationships, Income’s positive effect on RWB was the only one to have a practically (low) significant effect size. Being a Person of Color related to higher use of Fatalism, which had a low effect size. Higher use of Fatalism predicted higher RWB, which was a statistically significant effect, as well as a low practically significant effect. The disturbances of Forbearance and Fatalism were covaried to account for social desirability and response bias. The final model showed adequate fit $\chi^2 (12) = 18.285, p = .107$, CFI = .978, NNFI = .961, RMSEA = .037 (90% confidence interval = .000 - .069), and SRMR = .051.

There was an inconsistent significant mediation effect, wherein Fatalism partially mediated the relationship between Income and RWB (Standardized direct effect = .329, $p < .001$; Standardized indirect effect = -.036, $p = .004$; Standardized total effect = .330, $p < .001$). In this mediation, Income’s positive direct effect on RWB is inconsistent with the co-occurring negative indirect effect such that high Income predicts lower use of Fatalism, which thereby predicts decreased RWB. This mediation effect was deemed to have a low effect size. The mediation effect of Forbearance on the relationship between Stigma and RWB was not significant (Standardized indirect effect = -.029, $p = .024$).
Figure 3. SEM path diagram for Relational Well-Being (RWB) with ML standardized regression coefficients

Path Analyses for Personal Growth (PG)

Table 11

Maximum Likelihood Parameter Estimates for Initial PG Model

<table>
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<tr>
<th></th>
<th>Est.</th>
<th>Stand. Est.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>p</th>
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<tr>
<td>Engagement</td>
<td>-.098</td>
<td>-.077</td>
<td>.064</td>
<td>-1.539</td>
<td>.124</td>
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<td>Diseng.</td>
<td>-.094</td>
<td>-.081</td>
<td>.055</td>
<td>-1.698</td>
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<td>-.037</td>
<td>-.034</td>
<td>.056</td>
<td>-.670</td>
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<td>Forbearance</td>
<td>-.068</td>
<td>-.072</td>
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Table 12

Maximum Likelihood Parameter Estimates for Final PG Model

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Table 13

Covariances for Final PG Model

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Family Strains was significantly covaried with Parent Age and Stigma. Race was not significantly covaried with any other exogenous variable. Higher parent age related to higher levels of PG and lower use of Disengagement. On the other hand, higher Family Strains and higher Stigma related to higher use of Disengagement, which in addition to having statistical significance, also both had low practical significance. Higher use of Disengagement thereby predicted lower levels of PG, which was also practically significant at a low level. Higher Stigma also predicted lower use of Engagement, while identifying as a Person of Color predicted greater Engagement use. Engagement thereby predicted higher PG. The disturbances of Engagement and Disengagement were covaried to account for social desirability and response bias. The final
model showed adequate fit $x^2 (10) = 12.430, p = .257$, CFI = .990, NNFI = .978, RMSEA = .025 (90% confidence interval = .000 - .064), and SRMR = .029.

All of the statistically significant mediation effects for this model were deemed practically significant with a low effect size. There was a significant mediation effect such that Disengagement partially mediated the relationship between Family Strains and PG (Standardized direct effect = -.102, $p = .072$; Standardized indirect effect = -.045, $p = .001$; Standardized total effect = -.044, $p = .437$). While the Family Strains did not have a significant direct effect on PG, this relationship was mediated by the indirect effect of Disengagement, wherein higher family strain predicts higher use of disengaged coping, which then predicts decreased PG. There was also a significant partial mediation effect of Disengagement on the relationship between Stigma and PG (Standardized direct effect = -.071, $p = .207$; Standardized indirect effect = -.035, $p = .002$; Standardized total effect = -.016, $p = .767$). There was not a significant direct effect between Stigma and PG, although this relationship was mediated by the indirect effect of Disengagement, wherein higher family strain predicts increased use of disengaged coping, which then predicts decreased PG. The mediation effect of Disengagement on the relationship between Parent Age and PG was not significant (Standardized indirect effect = .021, $p = .020$). Also, Engagement was not a significant mediator in the relationship between Stigma and PG (Standardized indirect effect = -.012, $p = .064$).
Figure 4. SEM path diagram for Personal Growth (PG) with ML standardized regression coefficients

Path Analyses for Purpose in Life (PL)

Table 15

Maximum Likelihood Parameter Estimates for Initial PL Model

<table>
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<tr>
<th>Path</th>
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<td>0.931</td>
</tr>
<tr>
<td>S. Activity</td>
<td>Race</td>
<td>1.826</td>
<td>0.123</td>
<td>0.746</td>
<td>2.448</td>
</tr>
<tr>
<td>Relational U.</td>
<td>Race</td>
<td>1.645</td>
<td>0.089</td>
<td>0.934</td>
<td>1.761</td>
</tr>
<tr>
<td>Fatalism</td>
<td>Race</td>
<td>2.638</td>
<td>0.201</td>
<td>0.648</td>
<td>4.069</td>
</tr>
<tr>
<td>Fam. Support</td>
<td>Race</td>
<td>1.354</td>
<td>0.088</td>
<td>0.775</td>
<td>1.748</td>
</tr>
<tr>
<td>Intra. Coping</td>
<td>Parent Age</td>
<td>-0.038</td>
<td>0.039</td>
<td>0.050</td>
<td>0.770</td>
</tr>
<tr>
<td>Intra. Coping</td>
<td>Fam. Strains</td>
<td>0.049</td>
<td>0.068</td>
<td>0.036</td>
<td>1.351</td>
</tr>
<tr>
<td>Intra. Coping</td>
<td>Stigma</td>
<td>-0.003</td>
<td>0.001</td>
<td>0.112</td>
<td>0.025</td>
</tr>
<tr>
<td>Intra. Coping</td>
<td>Parent Edu</td>
<td>0.514</td>
<td>0.066</td>
<td>0.396</td>
<td>1.299</td>
</tr>
<tr>
<td>Intra. Coping</td>
<td>Race</td>
<td>1.526</td>
<td>0.090</td>
<td>0.858</td>
<td>1.778</td>
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<tr>
<td>PL</td>
<td>Parent Age</td>
<td>0.136</td>
<td>0.134</td>
<td>0.046</td>
<td>2.926</td>
</tr>
<tr>
<td>PL</td>
<td>Parent Edu</td>
<td>0.615</td>
<td>0.076</td>
<td>0.368</td>
<td>1.671</td>
</tr>
<tr>
<td>PL</td>
<td>Engagement</td>
<td>0.105</td>
<td>0.131</td>
<td>0.041</td>
<td>2.525</td>
</tr>
<tr>
<td>PL</td>
<td>Diseng.</td>
<td>-0.193</td>
<td>-0.220</td>
<td>0.047</td>
<td>4.106</td>
</tr>
<tr>
<td>PL</td>
<td>R. Authority</td>
<td>0.125</td>
<td>0.138</td>
<td>0.056</td>
<td>2.239</td>
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<tr>
<td>PL</td>
<td>Forbearance</td>
<td>-0.035</td>
<td>-0.033</td>
<td>0.059</td>
<td>-0.605</td>
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<tr>
<td>PL</td>
<td>S. Activity</td>
<td>0.018</td>
<td>0.015</td>
<td>0.066</td>
<td>0.268</td>
</tr>
<tr>
<td></td>
<td>Est.</td>
<td>Stand. Est.</td>
<td>S.E.</td>
<td>C.R.</td>
<td>p</td>
</tr>
<tr>
<td>------------------</td>
<td>------</td>
<td>-------------</td>
<td>------</td>
<td>------</td>
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</tr>
<tr>
<td>PL ← Relational U.</td>
<td>-0.44</td>
<td>-0.46</td>
<td>0.056</td>
<td>-0.774</td>
<td>.439</td>
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<tr>
<td>PL ← Fatalism</td>
<td>0.143</td>
<td>0.107</td>
<td>0.072</td>
<td>1.998</td>
<td>.046</td>
</tr>
<tr>
<td>PL ← Fam. Support</td>
<td>-0.30</td>
<td>-0.26</td>
<td>0.066</td>
<td>-0.450</td>
<td>.653</td>
</tr>
<tr>
<td>PL ← Stigma</td>
<td>-0.208</td>
<td>-0.091</td>
<td>0.108</td>
<td>-1.918</td>
<td>.055</td>
</tr>
<tr>
<td>PL ← Fam. Strains</td>
<td>-0.120</td>
<td>-0.164</td>
<td>0.034</td>
<td>-3.498</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>PL ← Intra. Coping</td>
<td>0.009</td>
<td>0.009</td>
<td>0.055</td>
<td>0.170</td>
<td>.865</td>
</tr>
</tbody>
</table>

Table 16

*Maximum Likelihood Parameter Estimates for Final PL Model*

<table>
<thead>
<tr>
<th></th>
<th>Est.</th>
<th>Stand. Est.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSI Diseng ← Stigma</td>
<td>0.565</td>
<td>0.211</td>
<td>0.140</td>
<td>4.038</td>
<td>&lt;.001</td>
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<tr>
<td>CSI Eng ← Stigma</td>
<td>-0.360</td>
<td>-0.125</td>
<td>0.140</td>
<td>-2.572</td>
<td>.010</td>
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<tr>
<td>CC_RA ← Race</td>
<td>3.133</td>
<td>0.163</td>
<td>0.965</td>
<td>3.247</td>
<td>.001</td>
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<tr>
<td>CSI Diseng ← Parent Age</td>
<td>-0.126</td>
<td>-0.106</td>
<td>0.054</td>
<td>-2.335</td>
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<tr>
<td>CSI Diseng ← Fam. Strains</td>
<td>0.193</td>
<td>0.226</td>
<td>0.044</td>
<td>4.415</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>CSI Eng ← Race</td>
<td>2.367</td>
<td>0.108</td>
<td>1.066</td>
<td>2.221</td>
<td>.026</td>
</tr>
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<td>PL ← CSI Eng</td>
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<td>0.149</td>
<td>0.039</td>
<td>3.066</td>
<td>.002</td>
</tr>
<tr>
<td>PL ← CSI Diseng</td>
<td>-0.198</td>
<td>-0.227</td>
<td>0.044</td>
<td>-4.545</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>PL ← Fam. Strains</td>
<td>-0.145</td>
<td>-0.195</td>
<td>0.036</td>
<td>-4.074</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>PL ← CC RA</td>
<td>0.132</td>
<td>0.142</td>
<td>0.043</td>
<td>3.047</td>
<td>.002</td>
</tr>
<tr>
<td>PL ← Parent Age</td>
<td>0.142</td>
<td>0.137</td>
<td>0.047</td>
<td>3.022</td>
<td>.003</td>
</tr>
</tbody>
</table>

Table 17

*Covariances for Final PL Model*

<table>
<thead>
<tr>
<th></th>
<th>Est.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stigma ← Fam. Strains</td>
<td>17.777</td>
<td>2.170</td>
<td>8.192</td>
<td>.455</td>
<td>&lt;.001</td>
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<tr>
<td>Fam. Strains ← Parent Age</td>
<td>-11.745</td>
<td>4.057</td>
<td>-2.895</td>
<td>-.133</td>
<td>.004</td>
</tr>
<tr>
<td>e1 ← e2</td>
<td>-23.372</td>
<td>4.594</td>
<td>-5.088</td>
<td>-.268</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>e1 ← e3</td>
<td>22.293</td>
<td>4.610</td>
<td>4.836</td>
<td>.254</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>e2 ← e3</td>
<td>-.086</td>
<td>3.870</td>
<td>-.022</td>
<td>-.001</td>
<td>.982</td>
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Table 18

*Fit Criteria for PL Model Respecifications*

<table>
<thead>
<tr>
<th>Step</th>
<th>$x^2$ goodness of fit</th>
<th>CFI</th>
<th>NNFI</th>
<th>RMSEA/ [90% CI]</th>
<th>SRMR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Original with covaried coping factor disturbances</td>
<td>131.446</td>
<td>.892</td>
<td>-.029</td>
<td>.169/ [.143, .195]</td>
<td>.056</td>
</tr>
<tr>
<td></td>
<td>$df = 11$</td>
<td>$p &lt; .001$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Trim non-significant coping variables</td>
<td>132.417</td>
<td>.654</td>
<td>-.131</td>
<td>.169/ [.144, .196]</td>
<td>.087</td>
</tr>
<tr>
<td></td>
<td>$df = 11$</td>
<td>$p &lt; .001$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Trim non-significant demographic variables</td>
<td>105.829</td>
<td>.700</td>
<td>-.201</td>
<td>.191/ [.160, .225]</td>
<td>.087</td>
</tr>
<tr>
<td></td>
<td>$df = 7$</td>
<td>$p &lt; .001$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Covary significantly correlated exogenous variables</td>
<td>9.828</td>
<td>.985</td>
<td>.918</td>
<td>.050/ [.000, .096]</td>
<td>.023</td>
</tr>
<tr>
<td></td>
<td>$df = 5$</td>
<td>$p = .080$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Trim non-significant regression paths</td>
<td>17.143</td>
<td>.984</td>
<td>.964</td>
<td>.033/ [.000, .066]</td>
<td>.030</td>
</tr>
<tr>
<td></td>
<td>$df = 12$</td>
<td>$p = .144$</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Family Strains was significantly covaried with Parent Age and Stigma, while Race was not significantly covaried with any other exogenous variable. Higher Stigma related to lower use of Engagement and higher use of Disengagement. Out of these two effects, Stigma’s positive effect on Disengagement had low practical significance. Stigma was not significantly directly related to PL. Higher use of Engagement was related to increased PL. Higher Family Strains related to decreased PL and higher use of Disengagement, with both effects being statistically and practically significant (low effect size). Higher Parent Age also related to lower use of Disengagement. Higher use of Disengagement related to decreased PL, which had a low effect size. Higher Parent Age related to increased PL. Identifying as a Person of Color related to
higher use of Engagement and Respect for Authority. Between these effects of race onto coping factors, the positive effect of being a Person of Color on Respect for Authority was practically significant (low effect size). Higher use of Respect for Authority thereby related to increased PL. The disturbances of Engagement, Disengagement, and Respect for Authority were covaried to account for social desirability and response bias. The final model showed adequate fit $x^2 (12) = 17.143$, $p = .144$, CFI = .984, NNFI = .964, RMSEA = .033 (90% confidence interval = .000 - .066), and SRMR = .030.

All of the statistically significant mediation effects for this model were deemed practically significant with a low effect size. The mediation of Disengagement on the relationship between Parent Age and PL was not significant (Standardized indirect effect = .022, $p = .021$). However, Disengagement was a significant partial mediator in the relationship between Family Strains and PL (Standardized direct effect = -.221, $p < .001$; Standardized indirect effect = -.048, $p = .001$; Standardized total effect= -.159, $p =.002$). In the direct effect, Family Strains negatively predicted PL; however, this relationship was partially mediated by Disengagement such that higher family strain predicts higher use of disengagement coping, which thereby decreases PL. There was no significant direct relationship between Stigma and PL (Standardized direct effect = -.090, $p = .080$); however, this relationship was significantly mediated by Disengagement such that higher stigma predicted higher use of disengagement coping, which then predicted decreased PL (Standardized indirect effect = -.038, $p = .002$). Engagement did not significantly mediate the relationship between Stigma and PL (Standardized indirect effect = -.011, $p = .075$).
Figure 5. SEM path diagram for Purpose in Life (PL) with ML standardized regression coefficients

Path Analyses for Overall Model

Table 19

Maximum Likelihood Parameter Estimates for Initial Overall Model

<table>
<thead>
<tr>
<th></th>
<th>Est.</th>
<th>Stand. Est.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement ← Pile-up</td>
<td>-.094</td>
<td>-.159</td>
<td>.029</td>
<td>-3.211</td>
<td>.001</td>
</tr>
<tr>
<td>Coll. Coping ← Pile-up</td>
<td>.156</td>
<td>.113</td>
<td>.068</td>
<td>2.296</td>
<td>.022</td>
</tr>
<tr>
<td>Coll. Coping ← Race</td>
<td>.847</td>
<td>.166</td>
<td>.250</td>
<td>3.389</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Diseng. ← Income</td>
<td>-.075</td>
<td>-.104</td>
<td>.034</td>
<td>-2.224</td>
<td>.026</td>
</tr>
<tr>
<td>Engagement ← Income</td>
<td>-.084</td>
<td>-.115</td>
<td>.036</td>
<td>-2.333</td>
<td>.020</td>
</tr>
<tr>
<td>Coll. Coping ← Income</td>
<td>-.255</td>
<td>-.149</td>
<td>.084</td>
<td>-3.034</td>
<td>.002</td>
</tr>
<tr>
<td></td>
<td>Est.</td>
<td>Stand.</td>
<td>S.E.</td>
<td>C.R.</td>
<td>p</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------</td>
<td>--------</td>
<td>------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Engagement ← Race</td>
<td>.247</td>
<td>.113</td>
<td>.107</td>
<td>2.296</td>
<td>.022</td>
</tr>
<tr>
<td>Diseng. ← Pile-up</td>
<td>.218</td>
<td>.373</td>
<td>.027</td>
<td>7.960</td>
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<tr>
<td>Diseng. ← Parent Age</td>
<td>-.009</td>
<td>-.076</td>
<td>.006</td>
<td>-1.617</td>
<td>.106</td>
</tr>
<tr>
<td>Engagement ← Parent Age</td>
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<td>-.069</td>
<td>.006</td>
<td>-1.406</td>
<td>.160</td>
</tr>
<tr>
<td>Coll. Coping ← Parent Age</td>
<td>-.009</td>
<td>-.081</td>
<td>.014</td>
<td>-1.648</td>
<td>.099</td>
</tr>
<tr>
<td>Diseng. ← Parent Edu</td>
<td>.003</td>
<td>.003</td>
<td>.046</td>
<td>.057</td>
<td>.954</td>
</tr>
<tr>
<td>Engagement ← Parent Edu</td>
<td>.056</td>
<td>.056</td>
<td>.050</td>
<td>1.133</td>
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<tr>
<td>Coll. Coping ← Parent Edu</td>
<td>.123</td>
<td>.052</td>
<td>.115</td>
<td>1.061</td>
<td>.289</td>
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<tr>
<td>Diseng. ← Race</td>
<td>.017</td>
<td>.008</td>
<td>.101</td>
<td>.170</td>
<td>.865</td>
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<tr>
<td>Well-Being ← Coll. Coping</td>
<td>.238</td>
<td>.193</td>
<td>.058</td>
<td>4.081</td>
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<tr>
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<td>.079</td>
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</tr>
<tr>
<td>Well-Being ← Income</td>
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<td>.093</td>
<td>2.354</td>
<td>.019</td>
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<td>Well-Being ← Diseng.</td>
<td>-.594</td>
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<td>.148</td>
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<td>Well-Being ← Engagement</td>
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<td>Well-Being ← Parent Age</td>
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<td>.016</td>
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<td>.029</td>
</tr>
<tr>
<td>Well-Being ← Parent Edu</td>
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<td>.125</td>
<td>2.525</td>
<td>.012</td>
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<tr>
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<td>.031</td>
<td>.005</td>
<td>.275</td>
<td>.111</td>
<td>.912</td>
</tr>
</tbody>
</table>

Table 20

*Maximum Likelihood Parameter Estimates for Final Overall Model*
Table 21

*Covariances for Final Overall Model*

<table>
<thead>
<tr>
<th></th>
<th>Est.</th>
<th>S.E.</th>
<th>C.R.</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pile-up ↔ Income</td>
<td>-0.236</td>
<td>0.120</td>
<td>-1.969</td>
<td>-0.101</td>
<td>0.049</td>
</tr>
<tr>
<td>e1 ↔ e2</td>
<td>-0.245</td>
<td>0.047</td>
<td>-5.185</td>
<td>0.210</td>
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<tr>
<td>e1 ↔ e3</td>
<td>0.398</td>
<td>0.108</td>
<td>3.688</td>
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<td>e2 ↔ e3</td>
<td>0.467</td>
<td>0.116</td>
<td>4.038</td>
<td>-0.274</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Table 22

*Fit Criteria for Overall Model Respecifications*

<table>
<thead>
<tr>
<th>Step</th>
<th>$x^2$ goodness of fit</th>
<th>CFI</th>
<th>NNFI</th>
<th>RMSEA/ [90% CI]</th>
<th>SRMR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Original with covared coping factor disturbances</td>
<td>116.727</td>
<td>.742</td>
<td>.072</td>
<td>.166/ [.140, .194]</td>
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<tr>
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<td></td>
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<tr>
<td>2.</td>
<td>Trim non-significant coping variables</td>
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<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
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<tr>
<td>3.</td>
<td>Trim non-significant demographic variables</td>
<td>4.596</td>
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<tr>
<td>4.</td>
<td>Covary significantly correlated exogenous variables</td>
<td>.661</td>
<td>1.000</td>
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<td>.000</td>
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</tr>
<tr>
<td>5.</td>
<td>Trim non-significant regression paths</td>
<td>.698</td>
<td>1.000</td>
<td>1.058</td>
<td>&lt;.001</td>
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<td>p = .952</td>
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</tbody>
</table>

An overall model was run to determine the fit of part of the Double ABCX (McCubbin & Patterson, 1983), regarding the proposed mediated relationship of family pile-up of stressors and outcomes with coping as a mediating variable. Pile-up was defined by the sum of Family Strains and Stigma. Individualistic coping was differentiated by Engagement and Disengagement as
individual variables. While it would be theoretically parsimonious to combine these two into an Individualistic coping category, statistically, their effects would cancel each other out because they affect well-being outcomes in opposite ways. The adaption construct of the Double ABCX Model (McCubbin & Patterson, 1983) was represented by Well-Being, which was a sum of SWL, RWB, PL, and PG. Thus, the outcome variable is comprehensively composed of hedonic, psychological, and relational well-being. Income was also included as a significant demographic variable (as others did not significantly relate to the overall Well-Being outcome).

Income was significantly covaried with Pile-up. Higher Income predicted higher Well-being and decreased use of all coping categories (Disengagement, Engagement, and Collectivistic Coping). Identifying as a Person of Color predicted higher use of Engagement and higher use of Collectivistic Coping. Greater Pile-up was related to increased use of Disengagement, decreased use of Engagement, and increased use of Collectivistic Coping. Subsequently, higher use of Disengagement related to decreased Well-being, while higher use of Engagement and Collectivistic Coping related to increased Well-being. Amongst all of the aforementioned models, this model had the most practically significant effects (with low effect sizes). The only effects that were not deemed to be practically significant in the Overall Model were: Income onto Disengagement, Income onto Engagement, Pile-up onto Well-Being, Pile-up onto Collectivistic coping, and Racial Identification onto Engagement. The disturbances of Disengagement, Engagement, and Collectivistic Coping were freely covaried to account for social desirability and response bias. The final model was significant $x^2 (4) = .698, p = .952$, CFI = 1.000, NNFI = 1.058, RMSEA < .001 (90% confidence interval = .000 - .000), and SRMR = .008.
All of the statistically significant mediation effects for this model were deemed practically significant with a low effect size. There was a significant mediation effect of Disengagement on the relationship between Pile-up and Well-Being (Standardized direct effect = -.382, \( p < .001 \); Standardized indirect effect = -.063, \( p = .001 \); Standardized total effect = -.303, \( p < .001 \)), while Engagement (Standardized indirect effect = -.009, \( p = .170 \)) and Collectivistic Coping (Standardized indirect effect = .011, \( p = .200 \)) were not significant mediators on their own. Disengagement mediated the negative direct relationship between Pile-up and Well-being such that pile-up of family stressors predicted higher use of disengagement coping, which thereby predicted decreased well-being. In addition, the relationship between Income and Well-being was significantly partially mediated (Standardized direct effect = .144, \( p = .001 \)) by Disengagement (Standardized indirect effect = .024, \( p = .009 \); Standardized total effect = .162, \( p < .001 \)). Disengagement mediated the positive direct relationship between Income and Well-being such that higher income related to lower use of disengagement coping, which thereby predicted increased well-being. However, this relationship was not significantly mediated by Engagement (Standardized indirect effect = -.015, \( p = .013 \); Standardized total effect) or with all coping mediators present at the same time (Standardized indirect effect = -.015, \( p = .064 \)).
Figure 6. SEM path diagram for Overall Model with Race with ML standardized regression coefficients
CHAPTER FIVE

DISCUSSION

The current study adds to existing literature by exploring multiple conceptualizations and approaches to coping within a diverse sample of caregivers of disability. Prior to the current research, caregiver research focused mainly on Western mainstream theories such as Folkman and Lazarus’ (1980) problem versus emotion-focused coping or Tobin et al.’s (1989) engaged/active versus disengaged/passive coping. Furthermore, if cultural considerations were explored, they were limited to largely qualitative research on a specific race or cultural group. Thus, this study aimed to expand quantitative multicultural caregiver research to include alternative (mainstream Western and collectivistic) theories of coping with both European Americans and People of Color. More specific hypotheses were based in a component of the Double ABCX Model (McCubbin & Patterson, 1983), which predicts that coping mediates the relationship between pile-up of stressors and well-being.

Summary of Findings and Conclusions

Out of the tested models, the Overall Model demonstrated the best fit and strongest effect sizes, suggesting that this model may be the most meaningful to interpret. This model may suggest the use of holistic, bi-cultural approaches to coping and well-being in parents, or more specifically, mothers of children with disabilities. In addition to the Overall Model, there were also significantly and practically meaningful relationships worth noting and exploring further that arose from the specific well-being models. While some of the individual relationships between caregiver stress, coping, or well-being factors may be supported in past literature, no prior study examined these specific factors in an attempt to hypothesize a comprehensive model.
for parents of children with disabilities. Therefore, much of the SEM findings were exploratory in nature and were intended to address gaps in literature, develop understanding, and inform future directions of study.

**Relationship between Pile-up (X) and Well-Being (Y)**

Regarding the first research question about the direct relationship between Pile-up (Family Strains and Stigma) and Well-Being, the Overall model supported the hypothesis that Pile-up would have a negative predictive effect on Well-Being, such that higher amounts of stress on caregivers cause decreased well-being. What this result means in practice is that one standard deviation increase in Pile-up leads to a .3 standard deviation decrease in comprehensive (hedonic, eudaimonic, relational) well-being, which may be deemed a meaningfully low impact. This notion is supported by the conceptualization of Pile-up in the Double ABCX Model (McCubbin & Patterson, 1983), which posits that co-occurring stressors build onto the initial stressor (i.e., diagnosis or first symptoms of disability), which cause an overwhelming of current resources/systems and thereby requires changes in functioning.

More specifically, out of the four Well-Being factors, Family Strain was only directly predictive of Satisfaction with Life (SWL), Relational Well-Being (RWB), and Purpose in Life (PL). Family Strain’s effect on RWB and PL were the only ones that were practically significant (with low effect sizes) however, suggesting that for every standard deviation increase in Family Strains, RWB decreased by .35 standard deviations and PL decreased by .19 standard deviations. In addition, Stigma was only directly predictive of SWL out of all of the individual well-being factors. This relationship had a low effect size, wherein with each standard deviation increase in Stigma, SWL decreased by .24 standard deviations, meaning that parents who are affected by
and experience stigma may experience some direct subsequent impacts on their subjective well-being. However, the lack of significant direct relationships between stigma and well-being factors is likely rather due to inconsistent indirect effects (MacKinnon et al., 2000; MacKinnon et al., 2007) such that mediation processes suppress the natural relationship between stress factors and well-being. Therefore, Stigma may primarily affect well-being rather through mediating variables (i.e., coping).

The demonstrated direct links between caregiver stress and well-being highlight the importance of caregivers and providers to recognize the needs of the entire family, rather than focusing solely on the needs of the child. Wherein mothers are often found to be primary caregivers of children with disabilities, as represented in the overwhelming majority of the current sample, they are at risk for burn-out, depression, and other conditions that may compromise their well-being and health under high stress conditions (Bishop et al., 2007; Blacher & McIntyre, 2006; Skok et al., 2006). Therefore, management of stress and pile-up factors are imperative.

**Relationship between Pile-up (X) and Coping (M)**

In general, greater Pile-up significantly predicted all forms of coping, wherein higher experienced family burdens and stressors (Family Strains and Stigma) related to decreased use of Engagement and increased use of Disengagement and Collectivistic Coping methods. However, only the relationships between Pile-up and Disengagement (with 1 SD increase in Pile-up, there was a .37 SD increase in use of Disengagement) and Pile-up and Engagement (with 1 SD increase in Pile-up, there was a .16 SD decrease in use of Engagement) had practical significance. Therefore, when a parent experiences great distress due to child’s condition and
additive family stressors, it may incline them towards withdrawing from and also reducing efforts to address the problem or sources of stress directly.

In separating the components of Pile-up, Family Strains and Stigma both increase tendencies for parents to withdraw from interacting with the stressful environment associated with their child’s disability (i.e., Disengagement). These relationships had a low practical effect such that 1 SD increase in Family Strains resulted in a .23 SD increase in Disengagement, while 1 SD increase in Stigma resulted in a .21 SD increase in Disengagement. This pattern may be explained by the Yerkes-Dodson law (Yerkes & Dodson, 1908) of arousal-performance, which theorizes that there needs to be a prime (not too high or low) and manageable level of distress for people to perform at their optimal level. Perhaps the tendency for parents to use avoidant strategies to cope may indicate caregiver burn-out and a need to self-preserve under an overwhelming amount of stress. Aside from the impact of general caregiver stressors, the demonstrated effects of stigma on parents’ coping underscores the importance of unveiling the meaning of this relationship. It is possible that parents who perceive or experience high stigma towards disabilities in their social environment may internalize such stigma, and thereby detach themselves from the problem emotionally or foster methods of distraction in order to deal with or conceal their distress and protect against the threat of discrimination in the community.

On the other hand, Engagement was not significantly predicted by Family Strains. The fact that the level of Family Strains did not meaningfully associate with Engagement may suggest that caregivers may be inclined to manage caregiving challenges and fulfill necessary duties of raising a CWD, regardless of their experienced level of distress. Although Stigma’s negative effect on Engagement was statistically significant, it was not practically significant.
While this effect may not be apparent in observable in terms of “real life” impacts, it may still be relatively stronger than the insignificant relationship between Family Strains and Engagement because the effects of societal stigma may be more overwhelming and less amenable to change than the family stressors themselves.

Another significant relationship between Pile-up factors and Coping was that Family Strains uniquely and positively predicted Fatalism, or the acceptance of the situation through attributing meaning to it and having faith that problems will eventually work out. This finding suggests that when families experience high levels of stress, finding ways to accept the problem and recognize their limits of control over the situation is something that they commonly turn to. In support, studies have found that parents go through a process of renegotiating the meaning of their child’s disability through time (Gray, 2002; Gray, 2006) and even develop new perspectives on life (King et al., 2006). Nonetheless, this effect should be interpreted with caution, as the effect size did not meet practical significance—with 1 SD increase in Family Strains there was a .09 SD increase in Fatalism.

Lastly, Stigma uniquely and positively predicted Forbearance, or the tendency to withhold problems from burdening others. This effect had a meaningful, low effect size such that 1 SD increase in Stigma resulted in a .26 SD increase in use of Forbearance. To summarize the interpretation of the aforementioned effects of Stigma (which caused increased Disengagement, decreased Engagement, and increased Forbearance), these results collectively align with previous literature demonstrating that parents living in communities with highly stigmatizing views of disability protect their family from societal judgment and rejection through concealing the
child’s disability from others (Kunitz, 1983; McCallion et al., 1997; Saeternoe et al., 2001; Scior et al., 2013; Sheets et al., 2012; Zhou, 2000).

**Relationship between Coping (M) and Well-Being (Y)**

All of the coping styles (Engagement, Disengagement, and Collectivistic Coping) in the Overall Model significantly (statistically and practically) predicted overall Well-Being, with Engagement and Collectivistic Coping having positive effects and Disengagement coping having negative effects. This finding shows support that as opposed to Engagement strategies, which directly deal with the problem or stress at hand and hold a generally positive bias for its demonstrated effectiveness (Endler & Parker, 1990; Folkman et al., 1986, Lazarus & Folkman, 1984), indirect or alternative forms of coping may be represented and enacted in ways that have varying effects on well-being. Furthermore, the fact that CSI and CCS constructs were represented separately and caused different effects highlights the importance of emic approaches to fill in the gaps where individualistic lenses of coping may not suffice or be effectively universally applied. Collectivistic Coping strategies embody an array of what could be classified as active and passive coping methods from a culturally informed lens. In addition, it addresses the specific varieties of ways (e.g., Respect for Authority, Relational Universality) that social support may be effectively or preferably utilized by people who identify with a group as opposed to independently (i.e., for emotional or instrumental support).

**Satisfaction with Life (SWL).** The coping styles that significantly predicted SWL were Relational Universality, Engagement, and Fatalism. Relational Universality had a low practical effect on SWL (with 1 SD increase in Relational Universality, there was a .15 SD increase in SWL). The positive relationship between Relational Universality and SWL may be supported by
group theory that suggests that relating to other people who experience similar challenges is validating and decreases a sense of isolation (Yalom & Leszcz, 2005). Experiencing a sense of connectedness and relief in shared experiences that encompass burden and stigma may be particularly helpful for this population, who may not have adequate sources of social support who understand their unique stress. The benefits of relating to peers and not feeling alone in their experiences of caregiver stress may be particularly salient to this sample, who may have already been participating in support groups or organizations from which they were recruited for this study.

Engagement coping was found to predict SWL, which supports the findings of prior studies that deemed problem-focused coping as helpful (Bradley et al., 1991; Judge, 1998). Taking a proactive role in recognizing the stressors and directly managing the burdens of caregiving may enhance subjective well-being and happiness by addressing problems directly and decreasing the impact of the stressor, soliciting emotional support and reducing distress, and/or improving overall esteem and perceptions of agency over the situation. However, this result should be interpreted with caution, being that it did not meet practical significance.

Lastly, SWL was significantly predicted byFatalism, or the use of acceptance or creating meaning to cope with the struggles of having a CWD. However, this result should also be interpreted with caution, being that it did not meet practical significance. A parent’s belief in events having an underlying meaning or having faith that things will work out may especially align with Asian and Native American’s adherence to indigenous connectivity to their ancestors or Latino and African American’s trust in God and their faith. In the general population, finding spiritual meaning in the circumstances of a child’s disability has been noted to be a powerful
coping mechanism (Gray, 2002; Gray 2006). This finding highlights again, the importance of recognizing the nuances between widely acknowledged coping constructs within the CSI and those proposed in the culturally derived CCS. For example, although Fatalism may seem similar to Cognitive Restructuring (factor in Engagement) or Wishful Thinking (factor in Disengagement), there is a unique contribution accessed through Fatalism that captures one’s acceptance of the situation, rather than focusing on one’s positive or negative appraisals of the situation.

**Relational Well-Being (RWB).** The coping strategies that significantly predicted RWB were Forbearance and Fatalism, being two of the Collectivistic coping strategies. None of the CSI coping strategies were significant. These findings may be explained by the natural alignment of the CCS and the RWB measure, which are both grounded in emic, collectivistic standpoints, with foci on interpersonal connectedness and harmony. Fatalism had a low effect size such that with 1 SD increase in Fatalism, there was a .23 SD increase in RWB. An interpretation of this positive relationship could be that the more parents are able to accept, find meaning in their child’s condition, and let go of one’s need to entirely control the situation, the better their holistic bond to their culture, community, and family will be. From a collectivistic standpoint, being aware of one’s humble connectedness to his/her place/role in their community and world at large may both enhance one’s use of Fatalism and RWB.

On the other hand, the negative relationship between Forbearance and RWB is perhaps more complex to decipher, and seems counterintuitive. Where it would seem on the one hand that withholding disclosure and expression of distress to one’s social circle would be done to preserve social harmony for RWB preservation, perhaps doing so also disconnects one’s sense of
attachment to and inclusion in this social network and community. Furthermore, it may not be assumed that the goals of certain collectivistic coping strategies of caregivers are necessarily motivated by wanting to foster one’s well-being, but may be done so in a sacrificial way towards the welfare of the group as a whole, or to pursue one’s values amidst decreased well-being of the individual. While this effect may require further exploration to explain, it is worth noting that in spite of statistical significance, practical significance was not met, indicating that the relationship between Forbearance and RWB may not actually appear to be observable or meaningful.

**Personal Growth (PG).** PG encompasses feeling and striving towards further development and improvement over time. Engagement was demonstrated to have a significant, positive effect on PG. Understandably taking a more engaged, proactive approach towards caregiving stress and the problem associated with raising a CWD is suggested to positively impact personal growth. When caregivers are taking an active and direct role in solving the problems of their situation, it makes sense that they would be goal and improvement oriented, as they would be actively involved in enacting change as opposed to accepting complacency or satisfaction. However, this result should be interpreted with caution, with the understanding that it may not have a practically meaningful effect, given that 1 SD increase in Engagement resulted in a .14 SD increase in PG.

On the other hand, Disengagement was shown to have a significant and practically meaningful effect on PG (low effect size; 1 SD increase in Disengagement resulted in a .22 SD decrease in PG). This finding suggests that taking a more detached, back-seat approach to managing caregiving issues decreases PG, as they are not engaging in actions that promote change and growth. Taken together, implications of these findings may be that parents who are
solution focused as opposed to passive in handling their caregiver stress may become more highly motivated and feel inspired by their ability to work towards self-progress and improvement.

While a clear application of CSI coping constructs can be placed onto PG, it seems that coping strategies with the perspective of oneself in a group do not relate or appear salient, as evidenced by none of the CCS coping strategies being significant. This result may be explained by the idea that PG is a rather individualistic value for the purposes of attaining personal achievement and fulfillment.

**Purpose in Life (PL).** PL encompasses having purpose, meaning, and goals in life. PL had a combination of both individualistic and collectivistic coping strategies that were shown to be significant contributors, including Engagement, Disengagement, and Respect for Authority. Similar to the outcomes of the PG Model, Engagement had positive effects (with 1 SD increase in Engagement, there was a .15 SD increase in PL) and Disengagement had negative effects on PL (with 1 SD increase in Disengagement, there was a .23 SD decrease in PL), which were both practically significant with low effect sizes. One way to explain this finding is that that parents who take a more engaged approach in dealing with their stress and problems may have a sense of directedness in their life and be future oriented towards such purpose. On the other hand, parents who are problem avoidant and with lower tendencies to directly manage their stress may thereby feel lost in their direction in life and lack such purpose. The benefits of having a greater sense of purpose in life from taking an active role may serve as a very powerful existential experience, as many parents may have to recreate their meaning in being a parent and having a child after
encountering and attempting to resolve the dissonance between their former expectations and current experiences of raising their CWD.

Respect for Authority has an interesting relationship with PL such that higher Respect for Authority increases PL. From seeking the guidance and advice from elders or respected community leaders, parents may ease the existential anxiety in searching for meaning making or direction in their role of being a caregiver of a CWD and why they are faced with those challenges. In addition, it is possible that by seeking guidance from a respected figure in the community—whether that would be from an indigenous healer, religious leader, or an elder—may be beneficial in decreasing a sense of helplessness and increasing hope for their future. However, the practical effect of this relationship is slightly lower than that of the other coping indicators in this model, and may not be meaningfully significant.

**Mediation Effects**

The second research question is based in the hypothesis of the Double ABCX Model (McCubbin & Patterson, 1983) which posits that coping mediates the relationship between Pile-up and the adaptation of the family (i.e., Well-Being in this study). The Overall Model suggests partial support for this hypothesis, as many partial mediation effects were discovered. All mediation models demonstrated low effect sizes or practical significance.

By far the most frequent mediator that occurred, particularly for the psychological indicators of well-being (PG and PL), was Disengagement. Disengagement mediated the effect of risk factors, Family Strains and Stigma onto both PG and PL. In summary, the higher use of disengaged coping strategies heightens the negative effects of risk factors associated with experiencing stigma and family strain onto psychological well-being. Thus, for parents who
experience a significant pile-up of risk factors and stress, considering whether they are denying or avoiding problems associated with raising their CWD by perhaps self-blaming, wishing for something different, or socially withdrawing, may be important to be aware of and address in order to reduce negative psychological impacts.

Although Disengagement was the most common mediation factor discovered, Fatalism had partial mediating effects in both the relationship between Income and SWL and between Income and RWB. First, the direct effect of Income and SWL is supported by prior studies which demonstrate a positive (but diminishing) effect of income levels on subjective well-being, meaning that those who have greater financial means, particularly above the poverty line, show higher levels of subjective well-being (Diener & Ryan, 2009). Secondly, the finding of Income as a protective factor or positive predictor to RWB may be explained by the overlapping financial and health care components that are captured by RWB constructs. The mediation effect of Fatalism adds that those with higher income tend to utilize Fatalism less, perhaps because they have the means and access to resources to change their situation and advocate for their child’s treatment and success. Subsequently, decreased use of Fatalism from higher income decreases SWL, which works against the independent positive effects of Income and Fatalism on RWB and SWL. Taken together, the collectivistic practice of fatalism may have great meaning and use across cultures for caregivers. Parents may have varying levels of acceptance of their child’s condition and need for change that may affect their attitudes towards services for their child.

While community organizations, social workers, the education system, and other providers who work with parents of CWDs may emphasize behavioral plans and resources and opportunities for
children, appropriate uses of fatalism may be equally as important to maintain one’s sense of well-being.

Another significant indirect effect that was discovered was that Engagement partially mediated the relationship between Stigma and SWL. This mediation effect illustrates that the lowered sense of life satisfaction that results from encountering stigma of disability may be partially explained by the effect of stigma that reduces one’s inclination towards using engaged coping strategies, thereby decreasing SWL. Certainly, those in this sample group, who were recruited from and have thus connected to existing social services, may have already sought out and experienced positive effects from active coping, although they may have had to first overcome the effects of stigma that may stray them away from seeking help.

**Cultural Considerations of Coping**

Lastly, in reference to the third research question regarding the effect of racial identification on coping style preference, the model for overall Well-Being shows support for the hypothesis that People of Color endorse Collectivistic Coping styles more heavily. The Overall Well-Being model revealed that identifying as a Person of Color predicted use of Collectivistic Coping. In specific well-being models, identifying as a Person of Color significantly predicted Fatalism (in the SWL and RWB Model), Respect for Authority (in the PL Model), and Engagement (in the PG Model). Such coping strategies were designed from an emic approach based on a collectivistic cultural orientation and values that People of Color may identify with which are often left out of traditional, Western mainstream coping theories. Although Collectivistic Coping strategies may also be helpful to and utilized by the caregiving population
at large, this finding confirms that there are coping styles that may be particularly salient to People of Color.

In this study, Fatalism can be considered an adaptive coping mechanism particularly for People of Color. A parent’s belief in their child’s disability or their caregiver stress to have a greater meaning may align with People of Color’s adherence to indigenous connectivity to their ancestors in Asian and Native American cultures (Goodkind et al., 2015; Huang et al., 2009; Sage & Jegatheesan, 2010), Latino and African American’s use of spirituality (Chiang et al., 2004; Constantine et al., 2002; Koenig, 1998; Lee & Mason, 2013; Lee & Sharpe, 2007; Smith & Dust, 2006), and Eastern philosophy’s view about suffering as a condition of life (Palsane & Lam, 1996). Under these philosophical or spiritual influences, People of Color may practice acceptance over their child’s condition more than European Americans. This finding also highlights the importance of teasing out Fatalism from Disengagement. While engaged forms of coping that directly deal with the problem are highlighted as the favorable, effective approach to coping in past literature (Bradley et al., 1991; Judge, 1998), this study shows support for a certain aspect of indirect coping (i.e., fatalism) that can be culture specific, nuanced, and overall beneficial in promoting well-being.

In addition, racial identification predicted Respect for Authority, indicating that People of Color rely on or use Respect for Authority as a coping method more than their European American counterparts. People of Color who are rooted in collectivistic perspectives that are often constructed in hierarchical societal structures may value seeking advice or guidance from authority figures in the community who are deemed to have knowledge, wisdom, and influence (Yeh et al., 2003). People of Color’s use of seeking help from spiritual leaders or elders in times
of distress has been supported in past literature (Lee & Mason, 2013; Torsch & Xueqin Ma, 2000). In addition, seeking guidance from respected authorities within one’s cultural community may promote an existential purpose in life amidst caregiving stress that may require this kind of meaning-making explanation.

The use of Engagement was also significantly predicted by racial identification. People of Color utilized Engagement more than their European American parents of CWDs. On the other hand, the current study does not suggest that racial identity relates to the use of Disengagement/passive forms of coping. Although active and passive forms of coping within these populations have revealed discrepancy with cultural and situational variation, these findings contradict the majority notion that People of Color (with particular salience to Asian Americans) rely less on active and more on passive forms of coping due to values of preserving harmony, minimizing burden onto others, and saving face (Bjorck et al., 2001; Chang, 1996; Chang, 2001; Crockett et al., 2007; Diaz-Guerrero, 1967; Hawley et al., 2007; Kim et al., 2006; Lam & Zane, 2004; Lee & Mason, 2013; Matthews et al., 2006; Sheu & Sedlacek, 2004; Taylor, Sherman, et al., 2004; Tobin et al., 1989; Tweed et al., 2004; Wong et al., 2010).

Prior studies have suggested that collectivistic cultures, as represented more typically by People of Color, perceive greater social stigma towards disabilities, in addition to having a higher desire to conceal the disability (Kunitz, 1983; McCallion et al., 1997; Saettermoe et al., 2001; Scior et al., 2013; Zhou, 2000). As contrary to prior literature, racial identification had no effect on the use of Forbearance in this study, which may suggest that withholding one’s problems or caregiver stress may be less culturally influenced than the other significant coping strategies mentioned in this study. Interestingly as well, race was not correlated with stigma,
which is also surprising based on the aforementioned results from disability stigma literature with People of Color. A hypothesis to explain this finding is that although the reasons or reactions to stigma may vary cross-culturally, stigma towards CWDs in general may be experienced by the caregiver group as a whole.

One way to explain unpredicted findings regarding People of Color’s higher use of Engagement and no difference in use of Forbearance between racial groups is that there may have been a selection bias of participants within these cultural groups who have high socio-economic statuses and existing involvement in community programs or support groups from which they were recruited. Thus, for this particular subgroup of potentially highly acculturated People of Color that have already sought resources for their family, active and engaged coping may be more salient, while withholding their child’s disability may be less salient.

Another implication from the relationships between race and coping found in this study may be that wherein stereotypes may assume that People of Color may deal with stressful situations more indirectly, demographic considerations and variation may exist in relation to active coping, while passive forms of coping may be better captured by culturally influenced strategies that take into account one’s relation to their social group. It is also important to consider that substantial variance exists between and within racial and cultural groups which is likely not captured by the People of Color classification. Racial communities may have culture-specific forms of coping, such as John Henryism for African Americans (James et al., 1983), which were not accounted for in the coping measures used in this study.

As evident in the higher use of both Engagement and Collectivistic coping strategies by People of Color, it could also be proposed that they are exercising bi-cultural forms of coping.
To apply this notion further, one’s use or endorsement of individualistic and collectivistic forms of coping may exist on two co-occurring dimensions, rather than on a single dimension. Therefore, a parent can be high on his/her use of both engaged forms of coping and fatalism, for example.

Another explanation is that the use of coping among cultural groups for parents of CWDs may be influenced by ethnic culture as well as other group identities, such as being a parent of a CWD, wherein the socialization, context, and experiences of race, culture, and disability intersect. By introducing the identity of disability, the application of past multicultural coping literature may not be as clearly projected. For example, there may be another factor, perhaps the duty towards seeking resources and child care and treatment, to the subgroup of People of Color that elicits more proactive action (e.g., seeking professional help, advocating for child’s needs) that may contradict traditional cultural values of coping. On the other hand, while it was shown that People of Color endorsed group-oriented coping strategies more than European American parents, there was still a mediation effect of Collectivistic Coping on the relationship between Pile-up and Well-Being for the sample as a whole, highlighting the potential benefit of communally geared coping for caregivers in general, who may individually sacrifice for and be affected by the holistic functioning of the family. Furthermore, there may be overlapping of racial/cultural tendencies towards individualism and collectivism, as supported by one study that found that European Americans were equally individualistic as African Americans and Latinos, and equally collectivistic as Japanese and Koreans (Oyserman, Coon, & Kemmelmeier, 2002); hence another possible reason why predictions of distinctions between People of Color and European American coping preferences were not clearly supported.
Limitations

One of the biggest limitations of this study was its restricted sample size. The limited sample size may have decreased the chance that significant findings were found for coping styles between racial identified groups. In addition, the small sample size of People of Color resulted in having to consolidate individual People of Color groups (Asian American, African American, Native American, and Pacific Islander) into one. Although limited by issues with statistical power, the practice of combining racial groups is not theoretically or culturally appropriate to do, as People of Color represent such great diversity that it may be erroneous to assume homogeneity within such group. Ideally, without constraints on sample size, coping phenomena should rather be examined by applying or discovering theories in more specific cultures, which would reveal much more in depth, and rich understanding.

Another related drawback to this study is that it has limited generalizability. The most striking skew in terms of demographic representation is that 93.8% of the study’s participants were female caregivers (i.e., large majority being mothers). While this skew is not unique to caregiver and parenting studies in general, as fathers are largely underrepresented, it is important to note that the generalizability of this study is largely limited to female caregivers, and not parents or caregivers as a whole. Further research is warranted to understand the coping and well-being impacts of male caregivers.

Another consideration about generalizability is the racial representation in the U.S. population from which this sample was recruited. While the latest U.S. Census Bureau (2015) reported that the U.S. population in 2014 consisted of 77.4% European Americans, 13.2% Black/African Americans, 1.2% Native Americans, 5.6% Asian/Pacific Islanders, 17.4% Latinos,
and 2.5% multiracial individuals, the current sample’s distribution consisted of relatively less representation of European Americans (69.2%), Black/African Americans (4.1%), and Latinos (6.2%) and relatively higher representation of Asian/Pacific Islanders (11.4%) and Multiracial individuals (9.1%). The difference in racial representation between the national census and the current sample may reflect the study’s heavy recruitment from the Pacific Northwest and Hawaii communities in particular, with the metropolitan Pacific Northwest racial distribution being most similar to the sample. Therefore, while the recruitment of this study was conducted nation-wide, the generalizability of findings may be more appropriate to Northwest metropolitan areas of the U.S.

The study also represented a biased sample of mid-high socio-economic status, which could have possibly overshadowed differences between cultures and minimized true indigenous cultural effects of coping. The overwhelming majority of participants were recruited from a support group or program/organization for disabilities, either online or in the community. These participants, who were already connected to community resources or social media outlets may hold more positive attitudes towards help-seeking, disclosure or forbearance, and activism. Therefore, this group may have already benefited from and value Engagement forms of coping, including problem-solving, emotional expression, and social support. This sample bias may have excluded parents that are not proactively involved in community or public resources, who may be more greatly affected by stigma, favor disengaged or forbearance strategies of coping, or seek alternative cultural resources that were not accessed through this study (e.g., church, indigenous practices). Therefore, the variance of related factors (e.g., Engagement, Disengagement, Forbearance, Stigma) might have been limited by the effects of this sample bias.
Another reason why sample bias may have affected the results and potential lack of differences between racial groups was that most participants had a college degree and the income distribution was skewed towards annual household income being more than $100,000. The reason why socio-economic class factors may have been skewed upwards, higher than the U.S. median, is likely due the nature of the means from which participants were recruited. Because the survey was hosted online and heavy recruitment of participants via social media and listserves was used, parents were required to have access to the internet, a computer, and time to fill out this survey in order to participate in this study. Therefore, parents who have more limited economic resources, with potentially higher strain and greater needs, were likely excluded from this study. The variance of related factors of Family Strains, Income, and Well-Being may have been limited by this sample bias.

Another consideration regarding the interpretation of the results of this study is the cross-cultural validity of the measures used. As mentioned earlier, there are issues with etic research that apply theories or constructs of coping or well-being that are not culturally congruent or applicable to populations beyond that from which the measure was derived or normed. Most of the measures that were used in this study did not specifically mention the demographics of participants from which the measure was originally validated, highlighting uncertainty of how these measures can be applied. For instance, the Family Strains Index (McCubbin & Patterson, 1982) and Inventory of Stigmatizing Experiences (Stuart et al., 2015) are geared towards assessing family members’ stressful experiences without implied use to a specific particular population, and with limited subsequent research validating its cross-cultural utility. While the RWB II scale (McCubbin et al., 2013) is intended for use on indigenous populations, it is unclear
whether or not it is able to be applied to European Americans alike, while further validation studies are also lacking. On the other hand, the CCS (Yeh et al., 2003) is intended for use with persons from collectivistic as well as individualistic cultures; however, follow up studies have only applied this scale on single racial ethnic groups in each study without psychometric validation amongst groups (Allen & Smith, 2015; Wei, Yeh, Chao, Carrera, & Su, 2013). The CSI (Tobin, 1995) likewise lacks cross-cultural validation studies, with follow up studies focusing rather on its ability to discriminate clinical from non-clinical groups (Tobin, Holroyd, Reynolds, & Wigal, 1985). Relative to the aforementioned measures, the SWLS (Diener et al, 1985) and the SPWB (PG and PL; Ryff, 1989) have been studied to a greater extent in terms of its cross-cultural application and validation. While the original SWLS study did not discuss application to other races, one review suggested that existing data support use of cross-cultural assessment of life satisfaction, but recommend that further research continue to explore any differences in scores and implications of the meaning drawn from life satisfaction amongst cultural groups (Pavot & Diener, 1993). Since, there have been efforts to validate this measure in other languages, and to assess for the differences between national SWL. One study supported cross-national invariance (Whisman & Judd, 2016), while others suggested cultural variance in subjective well-being as a whole (Diener & Ryan, 2009). Therefore, there is a lack of consensus and need for further studies to examine the validity of the cross-cultural application of the SWLS, particularly regarding racial/cultural differences within the U.S. in which this study is based. The studies on the SPWB have some focus on cross-cultural application of these constructs internationally or in the U.S. However, this scale is more typically applied to specific populations in each study to measure well-being as an outcome. One study that did compare
racial group results (European Americans, African Americans, and Mexican Americans) of psychological well-being in the U.S. found that People of Color had greater psychological well-being as a whole than European Americans, after other factors were controlled for (Ryff, Keyes, & Hughes, 2003). However, the presence of perceived discrimination decreased the psychological well-being for women of color, demonstrating differences in the interaction of gender and race in additive stressful circumstances. Thus, further studies that would elucidate potential differences between groups to determine measurement/construct validity versus differences accounted for by other factors would be necessary to aid interpretation. The interpretation of coping similarities or differences between European Americans and People of Color in this study is thus challenged by and prompts caution due to the limits of measurement validation with untested invariance between populations.

In order to more accurately assess for cultural effects of coping, it would have been useful to examine acculturation or adherence towards indigenous cultural values instead of only racial identification and generation status. The lack of information regarding endorsement of cultural values and behaviors limits the interpretation of what contributes to preferences in coping strategies. A person’s identification as an Asian American, African American, or any other racial group of Color does not necessarily indicate that they endorse more collectivistic or individualistic orientations or values in general. Incorporating this possibly salient predictor variable may have helped to explain some of the unpredicted results found in this study. Thus, cultural values may be fruitful to examine in future multicultural caregiver coping and disability research.
From a statistical standpoint, this model should be tested in other diverse samples of caregivers of CWDs because of the exploratory nature of the study, which was theoretically framed, but empirically trimmed and modified. In particular, the use of covarying disturbances of coping factors improved model fit, which may indicate that the model does not in fact accurately represent reality. Furthermore, there may be other factors not included in the model, of which the current research hypothesized as response bias or social desirability, that would be useful to test and include in future models.

**Future Directions of Research**

While former caregiver research focuses primarily on etic, Western theories of coping (Folkman & Lazarus, 1980), this study shows the value of incorporating coping and well-being that may be relevant to both European Americans and People of Color, with particular attention to diverse samples. In addition, given that the range of well-being models, covering subjective, relational, and psychological forms of well-being, yielded completely different models and significant coping methods, illustrates the importance in recognizing that well-being is not a one-dimensional construct either. Interestingly, collectivistic coping methods were the only ones retained in the emic RWB Model, and the CSI coping methods were the only ones retained in the Psychological Well-Being model of PG. This difference further highlights the need for research to consider both emic and etic approaches to coping and well-being in order to fully acknowledge cultural lenses that may be ignored by heavy sole uses of etic approaches.

Another aspect of caregiver stress and resilience that was included in this study that would be useful for future models to incorporate is stigma. Stigma has been shown to be a significant predictor of well-being and different types of coping in this study for the population
of caregivers of CWD as a whole, regardless of their cultural background. The impact of such stigma adds an important, additional element to Pile-up of stressors, as it is not only dependent on individual appraisals of the situation, availability of resources, and demographic risk factors, but is also dependent on one’s interaction with their community, socio-cultural values and environment. The stress induced by how one or one’s community or society perceives disability cannot be undermined or ignored in raising a CWD. Further studies that examine stigma in relation to culture, coping, and well-being could be a fruitful, developing area of study in future research.

In addition, it would be important for future studies with diverse samples of intersecting identities to be conducted, as opposed to multicultural research that examines one dimension of diversity at a time. Those who are vulnerable to societal stressors and stigma often face additive layers of oppression from multiple marginalized identities (Crenshaw, 1999). Besides more quantitative research in this realm, support for qualitative research, that can elicit the cultural complexities of caregiving experiences as it intersects with racial identity and cultural values would be invaluable to uncover. Considerations of multicultural research from alternative, emic, mixed-method approaches would not only further promote cultural inclusion in research, but also in practice, so that at-risk, “double minority” groups can be served by culturally-sensitive and informed ways. Efforts to link this area of multicultural research to practice can help to improve the gap between mental health and help-seeking disparities.

Lastly, negotiating the rewards and challenges of raising a CWD is a continual, on-going process in which different coping methods and appraisals may be elicited at different stages. Thus, longitudinal studies would be able to effectively examine the progression of stress and
coping over time. While the Double ABCX Model (McCubbin & Patterson, 1983) helped to frame the current cross-sectional data into a linear trajectory of stress, coping, and well-being, using a longitudinal study design, the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin, & McCubbin, 1996) may alternatively be applied to reveal a more complex understanding of the multiple phases of adjustment that families cycle through.

**Applications**

This study underscores the importance of building awareness and attending to the caregiver stress of parents of CWD. Due to the demonstrated evidence of coping as a partial mediator between Pile-up or other indicators of risk and well-being, it is not only important for families, scholars, and practitioners to be aware of vulnerability factors (e.g., Income, Race, Strain, etc.), but also to consider how parents cope with their caregiving stress, as it is often also through these methods that well-being is affected. Following this notion, family intervention can first address vulnerability factors, with focus on decreasing caregiver burden/stress and increasing resources. Secondly, the support and development of helpful and culturally congruent coping methods can be another viable intervention in promoting the well-being of parents of CWDs.

In addition to implications that can be made for the general population of caregivers of CWD, this study underscores the need for culturally-sensitive family services. In order to promote and tailor multicultural family services, providers need to become mindful about the social-cultural influences on parents’ perceptions of their child’s disability and how those beliefs influence their well-being, needs, experience of stigma, and coping preferences. For example, one question that a provider may consider in a cultural assessment would be: What well-being
goals are important to the family? —Are they concerned more about personal happiness or growth, or that the family remains in relational harmony with their community? As demonstrated by the differing well-being models, the effectiveness of each coping strategy may be determined by what type of well-being is considered. Engaged and active forms of coping may be more beneficial for individualistic well-being goals (SWL, PG, PL), while collectivistic coping may be more beneficial for collectivistic/relational well-being goals (RWB).

In addition, professionals in the field should also become aware of each parent’s preferred cultural means of seeking help or services. As for People of Color, depending on levels of enculturation/acculturation, they may be more inclined to seek mentorship from elders or mentors in their cultural group rather than seeking professional help. Use of bi-cultural or culturally preferred methods for treating the child’s disability and managing caregiver stress should be respected and encouraged. Given the disparities of mental health service use between People of Color and European Americans, cultural competency training is highly important to not only retain the clients that seek services, but also to provide effective outreach in efforts to reach underserved and vulnerable populations.
REFERENCES


Dear Participant,

You are invited to participate in a study that examines the stressors, coping, and well-being in parents/caregivers of children with disabilities. “Disability” in this study refers to a diagnosed/unspecified condition which requires special needs services. From a cultural perspective, we are interested in examining the coping styles that are used to effectively manage caregiver stress, considering the unique challenges, values, and needs of this population.

Your participation in this study is voluntary. This study is not related to the program, department, or persons from which you were referred in any way. This research is a doctoral dissertation under the supervision of Associate Professor, Laurie McCubbin, Ph.D., at Washington State University.

Your participation in this study will consist of taking an online survey that will take about 20 minutes to complete. You have the right to not answer any of the questions at any time, and/or stop the survey at any time without penalty. The information/individual responses that you provide in this study will remain confidential. The study findings, which will be represented solely as aggregate (i.e., group) data, may be published and/or presented at national conferences. While this study does not require you to provide any identifying information (e.g., name) in order to ensure your anonymity, the online survey portal may collect IP addresses that can be linked to your survey responses.

After completing the survey, you may choose to enter into a drawing for one of three $100 gift cards from Amazon.com. Participation in this raffle is voluntary. Please note that the completion of this survey will automatically route you to the raffle's website, however, you may choose to exit out of that site if you do not wish to enter the drawing. To ensure confidentiality, the information you provide (email address) cannot be traced to your survey responses, as they will be maintained on separate survey websites.

This survey poses minimal risk for psychological distress. However, if by participating in this survey, you experience concern about your or your family/child’s health/well-being, you may consider contacting the following sources:

- Parent to Parent (P2P) Programs:
  - Phone: 1-800-821-5927
  - Website: http://arcwa.org/getsupport/parent_to_parent_p2p_programs

- Parent to Parent Power:
  - Phone: (253) 777-1475
  - Website: http://lieucrews.wix.com/parent2parentpower#!

- Answers for Special Kids Resource Line
  - Phone: 800-322-2588

If you have any questions regarding this study, you may contact any of the following people conducting this research project:

- Erin Okumoto at e.okumoto@email.wsu.edu
- Dr. Laurie McCubbin at mccubbin@wsu.edu
By participating in this survey, you are acknowledging that you are at least 18 years old and that you agree to the terms and conditions stated above. Please print this form if you wish to have a copy for your records. A copy of the group findings can also be requested upon completion of the survey.

Thank you for your time and consideration in this important study.

Sincerely,

Erin Okumoto, M.A.
Doctoral Candidate
Educational Leadership and Counseling Psychology
Washington State University
APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE

1. How did you hear about this study?
   - School system
   - Community organization/program/group
   - Family member/friend told me about it
   - Facebook/social media
   - Other (please specify) _____________________

2. What is your relationship to your child with special needs?
   - Mother
   - Father
   - Other Guardian (please specify) ____________

3. What is your age? (in years)______

4. What is your relationship status?
   - Single
   - Married
   - Divorced
   - Separated
   - Widowed

5. What is the race/ethnicity you identify with? (check ALL that apply)
   - ___ White/Caucasian
   - ___ Black/African American
   - ___ Asian/Asian American
   - ___ Latina/o/Chicana/o/Hispanic
   - ___ American Indian/Alaskan Native
   - ___ Pacific Islander
   - International (Please Specify Country of Origin:) ________________
   - Other and/or specific ethnic or cultural identities (e.g., Chinese, German, Mexican, Black Caribbean, Native Hawaiian, Tribal affiliation, etc.) ______________________________________________________________________

6. If applicable or known, what generation are you to the U.S.?
   - First-generation immigrant: I moved from another country to the U.S.
   - Second-generation: My parents moved from another country to the U.S. and I was born in the U.S.
   - Third-generation: My grand-parents moved from another country to the U.S. and I was born in the U.S.
   - Fourth-generation or greater: My great-grandparents (or higher generation) moved from another country to the U.S. and I was born in the U.S.
   - Not applicable/unknown
   - Other (Please specify:) ________________________________

7. What is the highest level of education you attained?
• Less than High School/Some High School
• High School diploma/GED
• Vocational/Trade School
• College degree (Bachelor’s/Associate’s)
• Graduate level degree (Master’s/Doctorate)

8. What is your household’s estimated average annual income?
• Under $10,000
• $10,000-$24,999
• $25,000-$49,999
• $50,000-$74,999
• $75,000-$99,999
• $100,000 or higher

9. How many people live in your household, including yourself? ______

10. What is the age of your child with special needs? (in years) ______

11. What is the gender of this child?
• Male
• Female
• Transgender
• Other (Please specify)_______________________

12. What is this child’s grade in school?
• Pre-Kindergarten
• Kindergarten
• 1st grade
• 2nd grade
• 3rd grade
• 4th grade
• 5th grade
• 6th grade
• 7th grade
• 8th grade
• 9th grade
• 10th grade
• 11th grade
• 12th grade
• Beyond 12th/graduated high school

13. What was your child diagnosed with to qualify him/her with special needs services? (Please check ALL that apply)
• Undiagnosed/Unspecified
• Developmental Delay
• Intellectual Disability
• Speech/Language Impairment
• Visual Impairment/Blindness
- Hearing Impairment/Deafness
- Emotional Disturbance
- Orthopedic Impairment
- Autism/Autism Spectrum
- Traumatic or Acquired Brain Injury
- Specific Learning Disability
- ADD/ADHD
- Other Health Impairment (please specify)__________________

14. How many years has it been since your child officially received this diagnosis?____
APPENDIX C

RAFFLE PAGE

Thank you for participating in this study of caregiver stress and coping in parents/caregivers of children with disabilities. Your participation is highly valuable to understanding and serving the needs of families like your own.

If you would like to participate in a raffle to win one of three $100 gift certificates to Amazon.com, please provide your contact information below, at which we can reach you in the case that you are selected.
(If you do not wish to enter this raffle, you may exit this page)

Email (required to enter raffle):___________________________________________

The contact information that you provide is not linked to your previous survey responses, and will remain confidential.

If you have any questions regarding this study or would like to receive a copy of the completed group results, you may contact any of the following people conducting this research project:
• Erin Okumoto at e.okumoto@email.wsu.edu
• Dr. Laurie McCubbin at mccubbin@wsu.edu

If by participating in this survey, you have experienced concern about your or your family/child’s health/well-being, you may consider contacting the following sources:
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• Parent to Parent Power: (253) 777-1475
  Website: http://lieucrews.wix.com/parent2parentpower#
• Answers for Special Kids Resource Line: 1-800-322-2588

Thank you again for your participation!

Erin Okumoto, MA
Doctoral Candidate
Washington State University, Counseling Psychology
e.okumoto@email.wsu.edu