

**Socio-cultural Perspectives of Latino Children with Autism and their Families**

by

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A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
(Social Work and Psychology)  
in the University of Michigan  
2013

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## **Dedication**

To my family, friends, and the children and families with whom I have had the opportunity to work. To my parents, Alfred and Christine Lopez, who have supported my educational endeavors and cared for me through the ups and downs of Epilepsy. Thank you for reminding me that God never gives you more than you can handle. To my amazing partner in life's adventures, Carlos. You have been a tremendous support system in an often too lonely journey. I love you and look forward to the many adventures that await us. To my beautiful, smart, sweet, and silly daughter, Araceli. Mija, you have made me feel the most amazing and precious love I could ever imagine. I am so lucky to have you join me in this accomplishment and make each day brighter.

A special note of gratitude to Tom and the other students in Ms. Gallus' 1999-2000 adapted physical education class. Meeting all of you in my high school senior year greatly changed my perspective of disability and perseverance. Thank you so much for showing me the acceptance I had never known. With appreciation to the children and families at the schools I worked in, seen in interventions, and who participated in these studies; each one of you has a story that deserves to be heard. I hope this dissertation and my future work gives you voice.

## **Acknowledgements**

I would like to acknowledge my committee members who provided their time and feedback for the improvement of my dissertation. A special thanks to Dr. Stephanie Rowley and Dr. Robert Ortega, my committee co-chairs. Your dedication to my professional development, the time you spent reviewing my work, and engaging in conversations about the academic journey is remarkable. Thank you Dr. Lorraine Gutierrez for agreeing to serve on my committee and your words of encouragement. With appreciation to Dr. Sandra Magaña for the collaboration opportunities and your excellent professional guidance. It is with your support and research opportunities that I have been able to complete a dissertation that encompasses topics at the core of my culture and interests. Your dedication to the Latino community and the great strides you have made to include them in research and meet their needs is highly commendable. A big thank you to my dissertation buddies, Elizabeth Thomason, Cathleen Clerkin, and Monica Foust. I am honored to have gone through the process with you. Elizabeth Thomason, you are absolutely amazing and I am very proud of you!

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## **Abstract**

Factors affecting disparities in early diagnosis and care for Latino children with autism spectrum disorders (ASD) are reviewed through a socio-cultural lens. Other models of disparities do not include the expansive factors that contribute to disparities among Latino children nor do they incorporate the family experience raising a child with autism. This dissertation provides a summary model that serves as a foundation for two studies. Study 1 applies the summary model to Latino families raising children with ASD. The findings suggest that Latina mothers reported lower levels of family burden and pessimism compared to White mothers and endorsed positively worded items on family well-being and functioning. Study 2 tests the feasibility of a novel intervention that blends evidence-based practices for autism with culturally informed practices to specifically meet the needs of Latino children and families. Spanish speaking Latina immigrant mothers of children with autism participated in two eight session modules about general autism knowledge and services, advocacy skills, and strategies to work with their children. Post-test data revealed mothers reported increased knowledge about autism, better understanding of how to advocate for their children and themselves, and increased efficacy in using intervention strategies compared to their pre-tests. Suggestions for future research in psychology, and social work practice to improve the development and implementation of policies for and practice with Latino children with ASD and their families are discussed.



## **Chapter I**

### **Disparities in Diagnosis and Treatment among Latino Children with Autism**

Autism is one of the most prevalent childhood development disabilities. The Centers of Disease Control (2012) estimates one in every 88 children is affected by autism. According to Dyches, Wilder, Sudweeks, Obiakor, & Algozzine (2004) "...family income, lifestyle, and educational levels do not affect the chance of autism's occurrence" (p. 212). Although a plethora of information is available about the possible causes, developmental trajectories of affected children, diagnosis and treatment services, there remains a significant gap in the age of diagnosis and treatment services among racial/ethnic minority children (Levy et al., 2003; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). The few studies that explored sociodemographic factors and autism reported discrepant findings on prevalence and service access and use across race, maternal education (Mandell et al., 2009), income (Porterfield & McBride, 2007), health insurance coverage (Kilbourne, Switzer, Hyman, Crowley- Matoka, & Fine, 2006), and residence (Mandell et al., 2009) among racial/ethnic minority children with autism. Children of racial/ethnic minority backgrounds who received a diagnosis often received alternative and lower quality services than white children (Levy et al., 2003; Mandell, Listerus, Levy, & Pinto-Martin, 2002).

The impact of poor care and support of underserved children is likely to lead to poor child outcomes and negative psychological and economic family outcomes. More research is necessary to better understand the processes underlying outcomes among children with autism from low-income, limited education, and/or racial and ethnic minority families as well as

strategies to improve diagnosis and treatment of autism among these populations (Interagency Autism Coordinating Committee, 2011).

The Latino<sup>1</sup> population presents a unique challenge to exploring disparities in diagnosis and treatment among underserved children with autism. The young, diverse, and growing population of Latinos is faced with a confluence of factors impacting disparities. Little is known about culturally specific factors and organizational factors contributing and protecting against disparities. The purpose of this chapter is to investigate disparities in diagnosis and treatment, as well as help-seeking and receiving with a focus on autism spectrum disorders (ASD; interchangeable with autism) among Latino children and families.

The Socio-Cultural Framework for Health Service Disparities (Alegría, Pescosolido, Williams, & Canino, 2011) frames the investigation with a particular focus on factors at the child, caregiver, and provider levels that contribute to the impact of autism on families. Treatment, service access and utilization are also examined across the child, caregiver, and provider levels

Chapter II provides a review of the literature pertaining to children's health disparities<sup>2</sup>, Latino children and families, and autism, as well as a summary model of factors contributing to the impact of autism on families and factors to consider in developing interventions for Latinos are provided with implications for Latino children with autism and their families.

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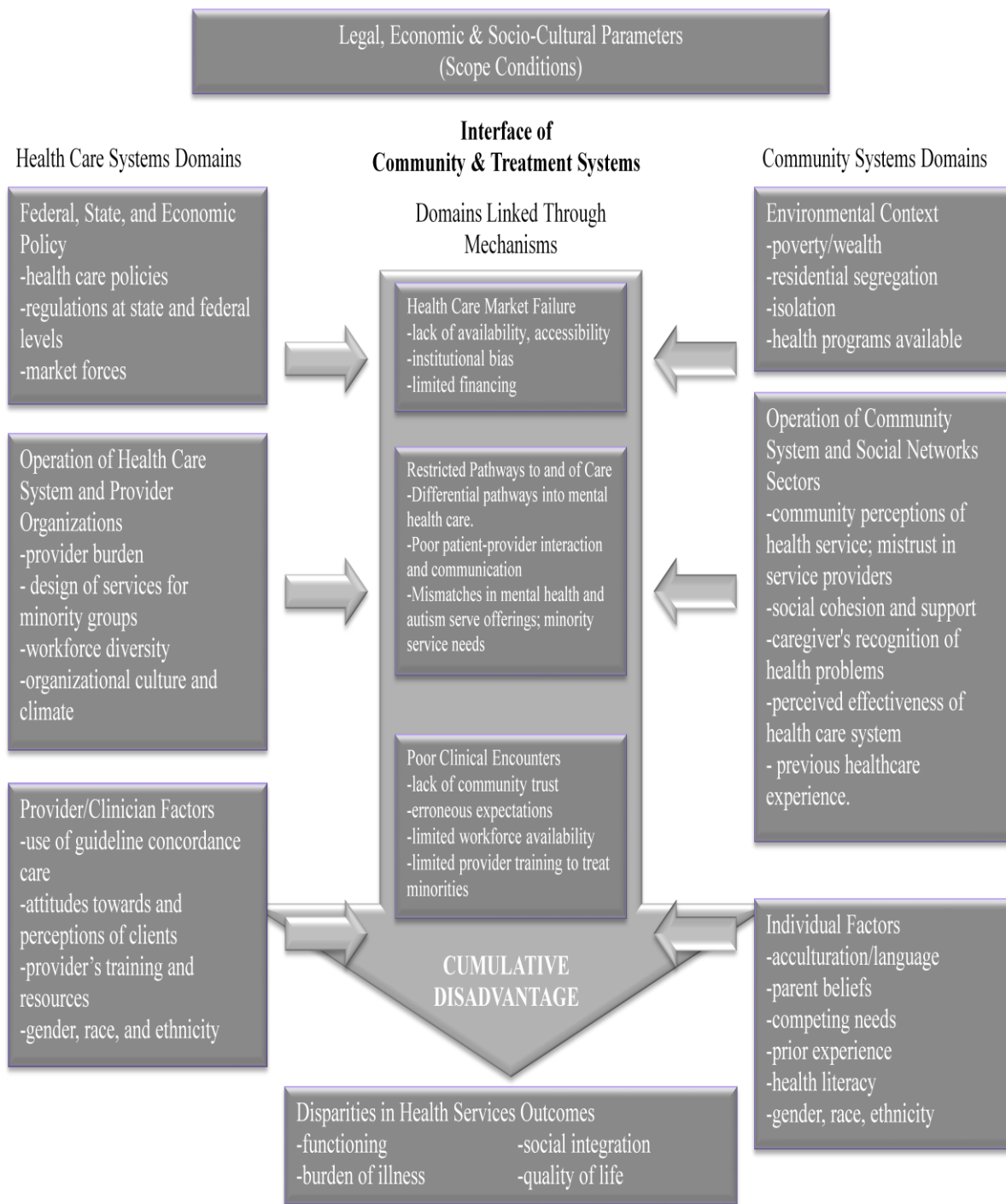
<sup>1</sup> The term Latino is utilized throughout the paper. However, several literature sources and data use the term Hispanic. Thus, the terms are interchangeable throughout the text depending on the reference. Most studies have lumped subgroups under the Latino or Hispanic labels without distinguishing among groups. Latino or Hispanic include any person of Latin-American origin or ancestry. Subgroups are Cuban, Mexican, Puerto Rican, South or Central American. Although Latinos are continually lumped into one category, each group and members within it have diverse experiences with treatment seeking, feelings of support, and service utilization that should be taken into account in the development of interventions to improve early diagnosis and treatment of Latino children with autism.

<sup>2</sup>The literature available for disparities in early diagnosis and treatment of Latino children with autism is limited. Therefore, research pertaining to Latino children with other developmental disabilities and chronic illnesses are included where appropriate.

Chapter III is an empirical study of the impact of autism on Latino families. Chapter IV investigates the feasibility of a culturally informed model of autism intervention for Latino families. Implications of the three papers in this dissertation specific to social work and psychology are included in Chapter V.

### **Framing Theory: Socio-cultural Framework for Health Service Disparities**

An ecological model is used to frame the available research on Latino children with autism and their families. Specifically, Alegría, Pescolido, Williams, and Canino's (2011) Socio-cultural Framework for Health Service Disparities (SCF-HSD) is the foundation for this dissertation. The framework was originally constructed to explain health disparities whereby Alegría et al. suggests that disparities are a function of multiplex disadvantage that involves culture, the individual, service systems and community. The SCF-HSD addresses factors at multiple levels (see Figure 1.1). Additionally, a major argument of the SCF-HSD is that culture is omnipresent and enacted which indicates the ever-changing impact of culture on health outcomes. The framework is broad, grounded in previous perspectives of disparities affecting Latinos, and offers insight about points of intervention to reduce disparities in mental and physical health. However, the SCF-HSD does not include factors specific to Latino children with autism and their families. The framework is a fruitful resource to understand this population of families, but requires a review of the literature and empirical work to isolate relevant factors. In this dissertation the SCF-HSD is used to identify specific variables that affect Latino family experiences raising a child with autism and to identify their unique contributions to interventions for Latino families of children with autism. Chapter II will broaden the SCF-HSD by considering the impact of child, family, and social support factors at the individual level that affect the impact of autism on families and guide the development of interventions for this population.



*Figure 1.1. Socio-cultural Framework for Health Service Disparities*

Two empirical studies that serve as initial steps to disentangling the plethora of factors affecting Latino children with autism and their families are included in Chapters III and IV. The first study offers insight about the SCF-HSD as it applies to the experiences of Latino families raising children with ASD. The second study provides an example of a culturally-informed model of intervention that addresses multiple gaps in the design of autism intervention that prevent them from being accessible to Latino families. A brief summary of each study is provided below.

### **Study 1: Family Burden among Latino Families with Children on the Autism Spectrum**

In Study 1 the experience of raising a child with autism is contextualized within the SCF-HSD. Data from the *Latino Families of Children on the Autism Spectrum project* were used to explore the impact of child and caregiver factors on mother-reported pessimism and family burden across the Latino and White families. The *Latino Families project* is a study conducted by Sandy Magaña at the University of Wisconsin. Study 1 is a secondary analysis was conducted using the project data with the permission of Dr. Magaña. The dataset includes information about experiences with diagnosis, services and unmet service needs among 48 Latino families (mostly mothers) and 59 non-Latino White families. Families were recruited through service agencies and support groups in Wisconsin. Preliminary analyses indicate Latino families experience less family burden than non-Latino White families (Lopez & Magaña, 2011). Additional findings indicate that child, caregiver, and family factors contribute to the relation between being Latino and family burden. Specifically, the number of behavior problems and caregiver pessimism are positively related to family burden, while family cohesion and optimism are inversely related to family burden. The findings suggest careful multi-factor investigation must be conducted to disentangle the factors affecting overall family experience among Latinos.

## **Study 2: Feasibility of a Culturally Informed Intervention for Latino Children with Autism**

In Study 2 the health care system domains within the SCF-HSD framework are investigated to explore the feasibility of an intervention designed to specifically meet the needs of Latino children and families affected by autism and their communities. The project, *Addressing the informational needs of Latino immigrant parents of children on the autism spectrum*, is a study conducted by a research team led by Sandy Magaña at the University of Wisconsin-Madison. Feedback about the content of the intervention and training of promotoras were provided by the author.. The project utilizes a promotora de salud (community health worker) approach to enhance caregiver understanding of autism, services, and strategies to work with their children. The promotora model includes the use of community healthcare workers to inform and deliver culturally-informed intervention services. The method has been found to be successful with the recruitment of Latino participants and the improvement of health education and outcomes (Balcázar, Alvarado, Hollen, Gonzalez-Cruz, & Pedregón, 2005). The intervention is based on the Ecological Validity Framework (Bernal, Bonilla, & Bellido, 1995). The framework emphasizes the role of *language, metaphors, content, persons, goals, methods*, and *context* in the adaptation of interventions for Latinos. Pre- and post-test caregiver data were used to test the feasibility of the intervention on caregiver knowledge of ASD, services, and intervention strategies. The information provides early evidence of the feasibility of a culturally informed, community centered, and cost-effective intervention for Latino families.

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## **Chapter II**

### **Modification of the Sociocultural Framework for Health Service Disparities**

The Socio-cultural Framework for Health Service Disparities (SCF-HSD) was developed by Alegría, Pescolido, Williams, and Canino's (2011), out of their recognition that previous research on health disparities report stagnant findings with little or no improvement in the understanding and reduction of health disparities. Alegría et al., define health disparities as “racial and ethnic differences in access, health care quality or health care outcomes that are not due to clinical needs or the appropriateness of treatment” (pg. 364). Alegría et al. postulated that disparities are exacerbated by barriers to access to health care systems, and the low quality and lack of availability of culturally sensitive treatment and service providers. A model of health disparities among racial/ethnic minorities is delineated to explain the multiple interacting factors that contribute to the persistence of health disparities.

Service utilization is dependent on the same factors that shape disparities, meaning that patients attend to the quality and content of services and provider interactions in their choice to use a given service. Community perceptions of the health care system also impact patient service utilization (Olafsdottir & Pescosolido, 2009). Alegría et al. assert that culture impacts health and health care among racial/ethnic groups. According to Alegría et al. identifying the unique contribution of cultural characteristics, traditions, values, and beliefs, as well as the role of societal perceptions of cultural groups provides insight about access, quality, and outcomes of health care among racial and ethnic groups.

Alegría et al. propose that racial/ethnic groups have community and treatment system experiences and routines at each stage of managing health and illness problems which fuel health

disparities. Varying levels of disadvantage and advantage, numerous social structures, and culture affect inequalities in health over the illness career. Furthermore, the points for intervention according to the SCF-HSD include the interaction points between community and treatment. The interaction points are broken down to three levels of analysis, the micro level (individual; provider or patient), meso level (organizational; formal organizations or lay sectors), and the macro level (societal; larger policy or environmental contexts).

Autism in this paper refers to a disorder that involves the cross sections of health, mental health, and educational systems. Latino children and families are the population of discussion. The SCF-HSD is the framework used to explore the host of factors that contribute to family experiences raising Latino children with autism and interventions for them. In their review of previous literature pertaining to cultural differences in diagnosis, acceptance, and treatment of ASD Bernier, Mao, and Yen (2010) identified the micro (individual level) and macro (societal level) factors including culture, that mediate outcomes for individuals with ASD. According to Bernier et al., there are a range of cultural factors impacting diagnosis, acceptance, treatment of ASD and treatment outcomes across cultural groups. A limited number of studies comment on the experience of Latino families raising children with autism. Furthermore, only a few case studies outlined possible interventions for these families. The dearth of studies suggest it is necessary to elaborate on the experiences of Latino children with autism and their families, to assist in the development of appropriate policies and practices to enhance culturally relevant diagnoses, acceptance, and treatment outcomes of Latino children with autism and their families.

### **Autism spectrum disorders**

Leo Kanner first described autism symptoms in 1943 based on observations he made of children with particular social deficits. Over a period of 68 years the disorder has been redefined, categorized, evaluated and treated in various ways<sup>3</sup>. Today autism is characterized as a neurodevelopment disorder marked by qualitative impairment in language development activities, and the presentation of restricted or routinized behaviors, and interests (APA, 1994). Onset of symptoms begins before three years of age. ASD can be reliably detected by 2 years of age (Lord, 1995). Symptom expression and severity vary across the life span (Lord & Spence, 2006).

In addition to changes in diagnostic criteria, the prevalence of autism has been met with rapid changes over the history of autism. In earlier years autism was considered an extremely rare disorder. For example in 1975 1 out of every 5000 children were reported to be affected by autism (Autism Speaks, 2011). The most recent estimate by the Centers of Disease Control (CDC, 2012) identified one in every 88 children as affected. Autism is one of the most prevalent childhood development disabilities. The dramatic increase in diagnostic rates have been attributed to changes in survey procedures, improvements in diagnosis, and a greatly expanded public awareness of behavioral and developmental disorders (Newschaffer & Curran, 2003). The rates have also prompted a focus on early diagnosis and treatment to deter the impact of autism on children and families.

Early diagnosis and subsequent treatment are critical to optimizing outcomes for children with ASDs (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Howard, Sparkman,

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<sup>3</sup>The criteria listed here is based on the autism spectrum disorder criteria from the Diagnostic and Statistical Manual-Fourth Edition Revised (DSM-IV; APA, 1994). Presently, the DSM-IV is under review with expected changes to the autism category. It is expected that autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified which are listed are separate disorders in DSM-IV, will be subsumed into a single autism spectrum disorder category. The change is proposed because each of the disorders share symptom criteria to varying degrees of severity. Officials overseeing the changes suggest, "...a single spectrum disorder is a better reflection of the state of knowledge about pathology and clinical presentation".

Cohen, Green, & Stanislaw, 2005; National Research Council, 2001). Ideally, a child should be diagnosed before age three (Corsello, 2005; Kelley, Naigles, & Fein, 2010). Speech delays are the most common cause of initial referrals for ASD and parent concern (Lord, Risi, & Pickles, 2004). Disturbances in the development of both verbal and other, non-linguistic social-communication behaviors have been shown in children diagnosed early on with ASD (Charman et al., 1997; Stone, Ousley, Yoder, Hogan & Hepburn, 1997). Language skills of children with ASD at age 2-4 years are the best predictors of adaptive skills at age 5 and outcome at adulthood (Lord et al., 2004).

Although no cure for autism is available, several types of biomedical, nonmedical, educational and evidenced-based interventions and treatments exist. The interventions vary in structure, frequency, targeted symptoms and behaviors<sup>5</sup>. It has been established that children who receive intervention before age three have better outcomes compared with children who receive treatment at later ages (Wetherby et al., 2004). Intensive behavioral intervention from ages 2-5 should be provided for maximum effectiveness which will reduce significant costs to the public (Jacobson, Mulick, & Green, 1998).

### **Disparities in early diagnosis of autism among underserved families**

Despite the emphasis on early diagnosis and treatment for children with autism there is evidence that a substantial number of children from traditionally underserved populations (i.e., racial/ethnic minority children and those living in poverty) are diagnosed and treated at later ages (Center for Disease Control and Prevention, 2012). However, other studies have shown no difference in prevalence rates of ASD. For instance, Yeargin-Allsopp et al. (2003) found similar

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<sup>5</sup>The full range of possible interventions is not discussed here as it is not the focus of this chapter. Readers are directed to Corsello (2005) for an extensive review of interventions and treatment models for individuals with autism.

prevalence rates across racial and class boundaries Still, Black and Hispanic/Latino children had lower odds of having a documented ASD classification than white children (Mandell et al., 2009). The age of first ASD diagnosis was significantly higher for African American and Hispanic/Latino children compared to white children (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Liptak et al., 2008). It is unknown whether the actual prevalence rates and access to care rates are lower for particular groups of children, or if social determinants of health contribute to the timing of diagnosis and treatment of children with autism. The variable findings demonstrate the need to explore autism across racial/ethnic groups as well as the contribution social determinants of health to early diagnosis and treatment among children with autism spectrum disorders. Disparities in service use across race, education, income, health insurance coverage, and residence persist for racial/ethnic minority children with an ASD diagnosis (Thomas et al., 2007). Children of racial/ethnic minority backgrounds often receive alternative and lower quality services than white children (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Mandell, Listerus, Levy, & Pinto-Martin, 2002). Early diagnosis and treatment are further impeded by the cost and availability of services (Kilbourne et al., 2006; Lord & Bishop, 2010), cultural and linguistic competency among providers (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009), parent-professional interactions (Mandell et al., 2009), and biased care systems (Liptak et al., 2008; Mandell, Novak, & Zubritsky, 2005). More research is necessary to better understand the processes underlying the outcomes of racial/ethnic minority children with ASDs and their families (Interagency Autism Coordinating Committee, 2011). A particular minority group that has been overlooked in autism research and underserved in practice is the Latino population. The Latino population is growing, diverse, and underrepresented in research on physical and mental

health (Surgeon General, 2001). Despite closing gaps between non-Latino Whites and other racial/ethnic groups, health care disparities persist among Latinos (Stone & Balderrama, 2008).

### **Latino children and families**

Between the 2000 and 2010 census the Latino population grew by 43 percent and encompassed more than half of the total population growth in the United States (U.S. Census, 2010). More than 50 million Latinos reside in the United States, with the Mexican origin population comprising 31.8 million, followed by Puerto Ricans (4.6 million), Cubans (1.8 million), and those of all other Hispanic origin (12.3 million). The median age of Latinos is lower than that of any other racial/ethnic group at 27 years of age. Native born Latinos average only 17 years of age. Latino children comprise 23.1% of children 17 years of age and younger. By the year 2050 Latinos are expected to make up 30% of the US population (Pew Hispanic Center, 2011). The Latino population within all fifty states has increased, with some states experiencing substantial growth such as South Carolina where Latinos grew by 148%. The majority of Latinos continue to reside in California, Texas, and Florida.

The population growth among Latinos was met with an increased number of families and children living in poverty. The Pew Hispanic Center reported that Latinos have the highest rates of poverty. Based on the Supplemental Poverty Measure, a new census measure that uses a wider range of factors than the official federal measure to determine poverty status, 28.2% of Latinos live in poverty (2011). The rate exceeds all other groups and the national poverty line of 16%. Latino children were hardest hit in the wake of the economic recession. Latino children experienced the greatest increase in poverty over the years of the recession, comprising 37.3% of all children living in poverty in the United States. The factors driving the high poverty rates include group expansion, birth rates, limited economic and educational opportunities, immigrant

status, and single parent households, (Pew Hispanic Center, 2011). Additionally, the majority of Latino children living in poverty have immigrant parents (4.1 million). Most children across the categories of parental backgrounds were born in the United States.

Educational attainment among Latinos lags significantly behind other racial/ethnic groups. Latinos have remained the lowest achieving group in education over the past four decades (Alfaro, Umaña-Taylor, & Bámaca, 2006). The educational disparity has been attributed to several individual, family, and school-related factors including higher risks of high school dropout, teen pregnancy, substance abuse (Freudenberg & Ruglis, 2007), disadvantaged educational experiences (Eamon, 2004), limited English proficiency (Martinez, DeGarmo & Eddy, 2004), low expectations and low college enrollment (Bohon, Johnson, & Gorman, 2006). Challenges to educational achievement begin in the early years. Across all levels of socioeconomic status fewer Latino children attend early educational programs than Black and White children (Flores & Zambrana, 2001). The accumulation of education disparities threatens the productivity and mobility of Latinos by way of reduced earnings, less skilled workforce, increased unemployment and greater need for services.

The number of Latinos with any given disability is estimated at 49,129,000 (U.S. Census, 2010). Given these characteristics they are likely to be seen in every sphere of the health, mental health and educational settings as well as informal systems. However, a conflux of factors across the micro, meso, and macro levels within health systems and communities affect access, service use, and receipt of diagnosis and services for young Latino children with autism. To explore the factors specific to Latino family experiences with autism and strategies to improve the development of culturally-informed interventions for Latino children with autism and their

families the socio-cultural framework for health service disparities is applied to the varying factors in the lives of Latino children and families.

### **Latino Children and Autism Disparities**

To outline the multitude of factors affecting Latino families and contributing to reduced service access and utilization two overarching questions are explored in this dissertation: *What variables at the micro, meso, and macro levels affect the impact of autism among Latino families? What variables at the micro, meso, and macro levels affect access and service utilization for Latino families, specific to autism?* Each of these questions are critical to identifying appropriate methods to approach the fastest growing group of children receiving autism diagnoses and engage them in interventions that meet their needs.

Latino parents rate their children's health status lower (Flores, Olson, & Tomany-Korman, 2005) than Black and White parents, yet Latino children are less likely to have health insurance and have limited access to care and quality services (Alegría, Vallas, & Pumariega, 2010). More specifically, Latino children are nearly two times more likely (22.7%) than all children (11.6%) to lack insurance (Flores, 2010). These conditions leave Latino children susceptible to a plethora of chronic illnesses and developmental delays (Flores, 2002; Flores & Zambrana, 2001). Specifically, studies that include large datasets to identify the prevalence of autism have pooled observations across all available years and adjusted for relevant sociodemographics (i.e., education, income) and known risk factors for autism indicate the risk of autism among Hispanics is higher than for non-Hispanic whites (Fountain & Bearman, 2011).

Latinos are less likely to utilize mental health services, despite existing mental health conditions (Carter-Pokras & Zambrana, 2001, pg 41). Thus, Latino children continue to have lower access, utilization, and quality of health care compared to white children once diagnosed



with an ASD or other developmental disability (Liptak et al. 2008). Additionally, Latino families have lower levels of satisfaction with specialty services (Bailey et al., 1999). The lack of access, utilization, and satisfaction of services magnifies the likelihood that Latino children with autism will have poorer physical and mental health outcomes compared with their White counterparts (Parish, Magaña, Rose, Timberlake, & Swaine, 2012).

Several multi-level factors affect access and utilization of health and mental health services that provide a gateway to autism intervention for Latino children with autism and their families. Alegría et al. (2011) outlined the factors associated with access and utilization disparities among Latinos in the socio-cultural framework for health service disparities. Similarly, Bledsoe (2008) reviewed factors affecting mental health service utilization among Latinos. Bledsoe found a multitude of factors across the individual, family, cultural, community, societal levels to either serve as a barrier or promoter of mental health utilization. The review is unique in that Bledsoe emphasized the interaction of factors and contexts affecting their position as a promoter *or* barrier to the utilization of mental health services among Latinos. Research, practice, and policy implications were suggested to increase the utilization of mental health services as well as the importance of surveying fundamental causes that situate Latinos to underutilize mental health services. Alegría et al. and Bledsoe highlight similar factors affecting Latinos across systems of care and the need to explore the factors as they contribute to the outcomes of health and mental health disorders among Latinos. Thus, it is suitable to use a socio-cultural framework to disentangle the factors affecting family experiences and to identify appropriate intervention methods for Latino children with autism. While Alegria et al. discuss individual outcomes such as functioning, social integration, burden of illness, and quality of life, this dissertation extends the framework to consider how factors at the micro and meso level

contribute to the burden of autism on the family (Study 1). Furthermore, the literature review provided in this chapter evidences several points of intervention to improve access to care for Latino families with autism that are illustrated in Study 2 which isolates many of the factors in the context of a culturally-informed intervention. Given that little research is available specific to Latino children and autism a review of literature pertaining to Latino children, mental health, health, and developmental disabilities is provided to modify the socio-cultural framework for Latino children with autism and their families.

### **The Micro-Level: Individual Level Factors Excluding Need or Clinical Appropriateness**

Latino children and families face numerous challenges that affect family burden as well as access and utilization of autism intervention at the micro level. The micro level includes child and family factors within the community system. For instance, child adaptive behavior levels, poverty (Carter-Pokras & Zambrana, 2001), educational disparities, and restricted access to health care (Flores, Abreu, & Kastner, 1998; Kataoka, Zhang, & Wells, 2002), parent immigrant status, acculturation levels, social isolation, language fluency, and knowledge about child development have been found to affect service access and use among Latino children (Alegría et al., 2004; Bailey et al., 1999). Additionally, Latino parents are often unaware of the availability of services (Lopez & Magaña, 2012; Magaña, Lopez, Aguinaga, & Morton, 2013). Paralleling the micro level community system is the health care system which includes provider/clinician factors. Provider/clinician factors comprise sociodemographic information about, attitudes towards clients, training, and resources. Together micro factors within the community and health systems contribute to cumulative disadvantage that negatively affect families.

#### **Micro Level: Child factors**

At the micro level several child specific factors affect family experiences and treatment utilization. The timing of onset and symptom expression contributes to the seeking of diagnostic services for children with ASD (Overton, Fielding, & Garcia de Alba, 2007). Children who express mild or subtle symptoms are often diagnosed later than those at the extremes of the spectrum (Lopez & Magaña, 2012). Social impairment, one of the core diagnostic symptoms of ASD, has also been shown to greatly impact early diagnosis among Hispanic children (Overton, Fielding, & Garcia de Alba, 2007). Additionally, children who appear to have regressed in their behavior and/or language development have different trajectories in the diagnostic process often including earlier diagnosis compared to children who do not display regression (Shattuck et al., 2009; Werner, Dawson, Munson, & Osterling, 2006). The level of symptom expression affects the family impact of autism, or family burden, as well as the likelihood of seeking and receiving intervention (LeCavalier, Leone, & Wiltz, 2006). For example, Gray (2002) found high levels of stress among parents of children who demonstrate aggressive or violent behaviors. Moreover, the amount of time associated with caring for a child with autism has also been found to be associated with lower levels of maternal well-being (Sawyer, Bittman, La Greca, Crettenden, Harchak, & Martin, 2010).

Age also plays a significant role on treatment access and receipt with younger children receiving more services than older children. This finding is attributed to the elevated concentration on early intervention with little attention focused on later ages of intervention. With regards to family burden, some research indicates greater burden on caregivers of older children with ASD than caregivers of young children,

In addition to symptom manifestation and age Latino children are faced with two social determinants of health that further contribute to deferred diagnosis and care, race/ethnicity and

poverty. The current literature indicates race and ethnicity contribute to delays in care with Latino children lagging significantly behind White children in service receipt. However, at the child level, race and/or ethnicity may interact with the child's socio-cultural context to influence the manifestation of symptoms and the delays in early diagnosis and treatment utilization among Latino children.

### **Micro Level: Caregiver factors**

In addition to child specific factors that affect the burden of autism on the family and treatment receipt, it is the suggestion of this dissertation that Latino caregiver factors be considered at the micro level. They are proposed to be in the micro level based on the proposition that caregivers are responsible for health and mental health related concerns for children with autism that affect burden and treatment. For example, Latino parents are less likely to report that their child has an autism diagnosis (CDC, 2006). Reasons for lower reporting and service use include parental health beliefs, limited maternal education, and parental knowledge of ASD. Denney, Itkonen, & Okamoto (2007) reviewed previous research on the experiences of Latino children and families involved with early intervention systems of care, defined as those nested under Part C of the Individuals with Disabilities Education Act (2004)<sup>4</sup>. Service barriers at the caregiver level included finances, linguistic and communication difficulties, and cultural incongruence between families and providers. Needs included more information about their child's health and access to services.

Family income contributes to the availability and affordability of health care. Latino children live in persistent and growing poverty more than children from another other

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<sup>4</sup>Part C: is a \$436 million program administered by States that serves infants and toddlers through age 2 with developmental delays or who have diagnosed physical or mental conditions with high probabilities of resulting in developmental delays.

racial/ethnic background. Their low-income status decreases access to affordable health care and adequate services (Flores, 2002; Zambrana & Logie, 2000). According to Hummer and Hamilton (2010) the greatest predictor of reduced health care access and utilization among Latino children is socioeconomic status. Specific to autism, variation in the type of treatment and specialty is related to family income levels, whereas children of higher income earners receive specialized treatment services at a higher rate than those from low-income families (Porterfield & McBride, 2007; Thomas et al., 2007).

Higher maternal education among mothers of children with autism may represent greater understanding of child development, service systems, and advocacy strategies resulting in earlier intervention and a wide range of care options (Mandell et al., 2009). Maternal education serves as a barrier for Latino children given the lower levels of maternal education among Latina mothers. For instance, Magaña, Lopez, Aguinaga, & Morton (2013) found maternal education to negatively impact the number of services Latino children with autism received. In the study 48 Latino families (mostly mothers) were interviewed in their homes about experiences with diagnosis, services and unmet service needs. Fifty-nine non-Latino White families completed a similar questionnaire. Maternal education and knowledge of autism were found to mediate the relationship between being Latino and service use. Moreover, low literacy skills serve as a barrier to successful navigation and functioning within the US health care system and are related to child health outcomes (Alegría et al., 2011; Flores et al., 2002; Zambrana & Logie, 2000).

Parental language fluency also affects service utilization among Latinos (Bailey et al., 1999). Using interviews Bailey et al. identified a pattern of needs across informational and social support domains among 200 Latino parents (50% Mexican, 50% Puerto Rican) caring for children with development disabilities. A greater number of overall needs among Latino parents

were found as compared to previous research on families of children with developmental delays. Language and degree of social isolation was found to impact the number of needs and forms of supports among the parents contributing to burden of the disorder on the family. Latino immigrants face a higher risk of reduced services given their limited status in the country due to language barriers, access to health services and financial support in addition to the absence of many protective factors (Carter-Pokras & Zambrana, 2001).

Parent beliefs about their child's mental health status and need for treatment services can hinder their awareness and use of services. For instance, Alegría et al. (2004) studied a community sample of 1885 Puerto Rican caregiver-child dyads with a high number of unmet mental health service needs. The researchers found that Puerto Rican parents' awareness of their child's symptoms of disorder largely contributed to service use. Their beliefs had a greater impact than other sociodemographics explored. The authors concluded that increasing use of mental health services among Latino youth requires the presence of supportive systems to accommodate the needs and beliefs of Latino parents raising children with mental health concerns.

### **Micro Level: Provider/Clinician Factors**

The practitioner's gender, race, and ethnicity may impact their interactions with children and families from different backgrounds. Concordant backgrounds among practitioners and patients may contribute to increased levels of comfort among patients and service utilization. Matching experiences and backgrounds also has the potential to enhance the practitioner's ability to relate to the impact of autism on Latinos.

Bias among practitioners influences early diagnosis and treatment among Latino children with autism (Flores, Olson, & Tomany-Korman, 2005). For instance, Mandell et al. (2009)

conducted a study on 2,568 children aged 8 years across 14 sites who met surveillance criteria for ASD through abstraction of evaluation records from multiple sources. Racial/ethnic background and SES of children were found to impact the likelihood of documentation of an ASD in children's records. For Latino children, the disparity was strongest among those with a comorbid intellectual disability. The findings suggest clinicians and other service providers do not push for an ASD diagnosis for Latino children in the presence of an intellectual disability leading to inappropriate treatment. Similarly, Mandell et al. (2009) found that racial/ethnic minority children received alternative diagnosis prior to receiving an ASD diagnosis at a disproportionate rate compared to White children. In this study, Mandell suggested providers prematurely diagnose children of racial/ethnic minority groups with alternate diagnoses on the basis of general prejudices held by the clinicians, stereotypes of their clients, and statistical discrimination.

Although Latino children are among the fastest growing population there is a distinct absence of proper training and understanding of Latino children's cultural norms and associated behaviors among clinicians. Cultural competency is not a central component of pediatric training programs (Flores, 2002). According to a comprehensive review of medical school curriculums in the United States, only 8% include training on culture while only 26% emphasize Latino culture (Flores, Gee, & Kastner, 2000). Under these circumstances clinicians may incorrectly apply rational algorithms on the likelihood of a child having ASD. The process of applying incorrect algorithms is termed statistical discrimination. Statistical discrimination often occurs when clinicians have different expectations about the probability of autism occurring in children of different ethnicities (Balsa & McGuire, 2001). Statistical discrimination may partially explain the differences in prevalence rates of autism among Latinos in different locations of the United

States. For instance, in 2006 the prevalence rate of autism among Latino children ranged from 0.6 per 1,000 in Alabama to 8.3 per 1,000 in Arizona (ADDM, 2009). It is likely that the unfamiliarity of Latinos among practitioners in Alabama explains the misdiagnoses of Latino children with ASD as compared to Arizona where practitioners had more contact with several Latino children over time.

Evidence-based treatment services specific to the experiences and needs of Latino children with autism and their families are not presently available. The lack of appropriate services coupled with the findings that Latino children are least likely of all racial/ethnic groups to attend early intervention services further reduces the chances of Latino children receiving important early intensive intervention services and increases the burden of autism on the family. Thus, many Latino children with autism do not receive services until they are filtered into the education system. In their study of Latino and non-Latino White children with autism Lopez and Magaña (2012) found that Latino children received special education services similarly to White children but had not received early services such as Birth to three or autism intensive services which they were eligible for. Given that Latino children are likely to receive later diagnosis they may enter the school system without an autism diagnosis. Many Latino children enter into underresourced schools, exacerbating their disadvantage in accessing quality diagnostic and treatment services (Jablonski, 2011). Underresourced schools may provide ineffective treatment plans, compounding less than optimal outcomes for Latino children with autism and creating greater family burden.

### **The Micro-Level: Provider–Client Interactions**

Interactions between providers and Latino families are associated with a mixture of factors that play a part in disparities. The factors include cultural incongruence, erroneous expectations,



and limited workforce availability. Cultural incongruence, or provider-client interactions that are nested in cultural differences impedes service utilization and quality of care (Furman et al., 2009; McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993). For instance, Denney, Itkonen, and Okamoto (2007) found that Latino families of children with special needs and their health care and early intervention providers had different ideas of child needs, cultural values, and parenting practices. The discrepancies in ideas and cultural values contributed to parents' utilization of services and parent/provider relationships. Cultural incongruence influences the level of mistrust among Latinos which has been found to contribute to the underutilization of the health and mental health care systems (Bailey et al., 1999; Furman et al., 2009).

### **The Meso-Level: Operation of the Health Care System and Provider Organizations**

Accompanying the meso-level factors within the community system are the meso factors within the health care system and provider organizations. Provider burden, design of services for minority groups, workforce diversity, and organizational culture and climate encompass the meso factors within the health care system and provider organizations. Snowden and Cheung (1990) suggest underutilization may be determined by the operational characteristics of the local delivery system. Many professionals in early childhood and early intervention services work with Latino children and families yet they feel unequipped to serve them (Buysse, Castro, West, & Skinner, 2005). Study 1 provides a perspective of the Latino family experience raising a child with autism to inform professionals about factors to consider when working with Latino families. Study 2 advances knowledge about culturally-informed strategies to utilize in the context of interventions. Both of the studies contribute to provider preparedness to work with Latino families raising children with ASD.

Workforce diversity is limited across the systems that serve Latino children with autism and their families. Specifically, bilingual providers are often inaccessible in many Latino communities (Alegría, Vallas, & Pumariaga, 2010; Derose & Baker 2000; Organista, 2007). Few Latinos hold positions of power to influence increases in access to care of Latino children with autism and their families. In recent years the number of Latinos enrolling in medical school has risen. However, the percentage of Latinos who have earned degrees in high education, professional degrees (i.e., MD, Law, MSW) and PhDs remains lower than the White and Black populations (National Center for Educational Statistics, 2010). Moreover, the ratio of Latino medical professionals to Latino patients evidences a significant gap. According to Flores (2002) reaching parity with the number of Latino pediatricians to Latino children would require more than doubling the number of Latinos in medical schools. The dismal reserve of Latino service providers (doctors, social workers, teachers, school psychologists, etc.) affects every level of the process to access diagnostic and treatment services for Latino children with autism. Thus, Latino children are left at a cumulative disadvantage to accessing comprehensive intervention services. Study 2 in this dissertation demonstrates a model of intervention that includes the use of Latino community health care workers, or promotoras. The use of a promotora model in intervention is an example of enhancing workforce diversity to meet the needs of Latino families.

### **The Meso Level: The Informal Community System – Family/Friend/Lay Network Sectors**

Alegría et al. (2010) asserts that micro factors interact with the meso level to intensify the disadvantage underserved populations experience within the health service systems. Similar to the micro level, the meso level operates at the community and health care systems. Within the informal community systems family, friend, and lay network sectors impact the burden of autism on the family in addition to access to and utilization of treatment services for Latino children

with autism and their families. For instance, social support and degrees of familismo (importance of family) contribute to the utilization of treatment services for Latinos (Blacher, Lopez, Shapiro, & Fusco, 1997). Underutilization of services may also be due to lack of understanding within the Latino population about the possible causes of emotional problems (Yeh, Hough, McCabe, Lau, & Garland, 2004). Repeated negative contacts with service providers are compounded by a lack of trust in key gateway providers such as teachers (Alegría et al., 2010). The pervasive lack of trust produces community-held beliefs in the avoidance of services.

Perceived effectiveness of the health care system is also dependent on the cultural background and cumulative encounters of racial/ethnic groups. Underutilization and premature termination of mental health services are frequent in the Latino population as a result of perceptions of therapy as not meeting clients' needs (Pinderhughes, 1989). In addition, culture mediates outcomes for individuals with ASD by impacting diagnosis, acceptance, and treatment of ASD (Bernier, Mao, & Yen, 2010; McCubbin et al., 1993). Latinos in particular, encounter stigma regarding mental disorders, difficulty in obtaining culturally sensitive services in their native language and a lack of belief in the effectiveness of available treatments (Flores, Abreu, Olivar, & Kastner, 1998). The design and implementation of culturally-informed treatment that addresses the cultural factors outlined here has the potential to decrease disparities in service use among Latino families raising children with autism. Study 2 in this dissertation speaks to this gap area and illustrates the feasibility of an intervention designed with the Latino culture, meso level factors, and autism as the foundation.

At the meso level parental perception of the child's mental health needs and parent perception of treatment efficacy impact service use. Parent perceptions of children's development, expectations for milestones, and understanding of children's needs for services are

dependent on cultural values. For instance, Garcia, Perez, and Ortiz (2000) interviewed seven Mexican American mothers of children with diagnosed language disabilities about their experience with early intervention services. The majority of the mothers did not believe their children had a disability. Thus, they were not as concerned for their child's development to seek extensive services. The mothers based their beliefs on prior experience with other children and family members. These factors are important to recognize, as they may impact decision to seek diagnosis and treatment of other developmental disorders such as autism.

Social support and cohesion are nested under the umbrella of the meso level as social network sectors. The degree to which parents are supported influences the impact of autism on the family and their involvement in treatment. One source of social support particularly relevant for Latinos is extended family. Latinos tend to rely heavily on extended family for social support (Bailey et al., 1999; Carter-Pokras & Zambrana, 2001). Immigration trends and policies at the macro level affect social support and networks for Latinos (Golding & Burnam, 1990). Latina mothers of children with developmental delays report higher levels of depressive symptoms, negative impact, and reduced treatment seeking for their children as a result of low social support (Bailey et al., 1999; Blacher, Lopez, Shapiro, & Fusco, 1997).

### **The Macro-Level: Federal State and Economic Policy and Environmental Context**

The macro level consists of health care policies and regulations at the state and federal levels that affect health care, mental health care, education, and autism-related services. Although the two studies below do not directly address the macro level, it is important to note the relevant factors at this level given that policies and regulations are guided by empirical work at the micro and meso levels. Market forces are created by economic policies and regulations governing health. After controlling for race, ethnicity, and needs health care coverage largely

affects children's health outcomes (Hummer & Hamilton, 2010; Shone et al. 2005). Health care regulations and eligibility criteria set by each state for public services such as Medicaid and the State Children's Health Insurance Program (SCHIP) or the Children's Health Insurance Program (CHIP), impacts access to health coverage for children. CHIP was designed to fill a gap in health care coverage by providing coverage to children from low-income families but who are not eligible for Medicaid. CHIP is a federal program administered by the United States Department of Health and Human Services that matches state funding for health insurance to families with children. According to the Agency for Healthcare Research and Quality National Healthcare Disparities report (2010) CHIP is an effective program in eliminating disparities in access across racial/ethnic groups of children. Despite success, the program has been met with challenges adequate funding and the recruitment and retention of eligible children. The economic downfall has led congress to enact policies that reduce funding to programs for children and families, including CHIP (SRCD developments, 2011). Children's programs constitute 20 percent of non-defense discretionary spending which puts them at risk for cuts. Diminished funding to programs such as CHIP, Head Start, and Special Supplemental Program for Women, Infants and Children (WIC) threatens affordability and access to health insurance for young children impeding access to treatment of autism subsequently increasing burden among families. Latino children are at a high risk for delayed services given that they disproportionately live in poverty and have a greater need for services. Two issues found to reduce the impact of CHIP on improving care includes challenges in the recruitment and retention of children in the program and eligibility criteria.

There is wide variation in the number of eligible children participating in CHIP across the states. For example, Nevada reports 53 percent of eligible children are enrolled, whereas

Vermont indicates 93 percent of eligible children and Arizona has no CHIP program. The disproportionate numbers specify a need for improved outreach efforts. Disparate eligibility criteria per state and accessible federal funding are two situations that have contributed to the diminished impact of CHIP on improving child health disparities (Shone et al., 2005). Eligibility in all states includes a citizenship requirement. The citizenship criteria, established in 2008, produced a loss and/or delay of services to thousands of Latino children. Thus, the potential advantages of using CHIP to increase access to care for autism may be impeded among Latino children in particular contributing to greater family burden.

Other policies and programs that affect access to care among Latino children are the autism-related policies in health, mental health, and education. There are differing opinions within these service systems about who is responsible for the cost of autism-related services. Much of the debate is rooted in the designation of autism as mental health impairment rather than a health problem. Thus, health insurers argue they are not responsible for coverage of treatment. Each state has different regulations and policies about the responsibility of care coverage and what types of care are covered<sup>5</sup>. Thirty four states and the District of Columbia have laws related to autism and insurance coverage. Twenty nine states have specific requirements for autism under the mental health parity act or other laws. Regarding Latino children who are most likely

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<sup>5</sup>The range of services covered by state is not within the scope of this paper. Please see <http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx> for a full review of the services covered by health insurance, mental health coverage, and other laws by state.

to be uninsured, these policies and laws leave them further disadvantaged in accessing treatment for autism and further burdening the family.

### **The Macro-Level: Communities**

The macro level concerns the community and broader social context in which Latino

children and their families reside. Latinos face several barriers to services within communities including an anti-immigrant climate (Fountain & Bearman, 2010) and availability of culturally informed bilingual service services (Buysse, Castro, West, & Skinner, 2005). Moreover, differences in problem recognition of mental health issues in the community and differential referral by the social network serve as potential precipitating factors to disparities (Flores & Zambrana, 2001).

Community-based efforts have uprooted in many areas of the US to supplement the lack of access to service needs among Latinos (Organista, 2007). Additionally, Latino-focused programs have been developed within community-based organizations/centers. Organista explained that the ideal model includes culturally and socially competent practice imbedded in the technology, personnel, and structures of programs. The critical elements suggested by Organista and embedded in the SCF-HSD are included in the culturally-informed intervention laid out in the intervention feasibility study in Chapter 4 of this dissertation. The study illustrates early evidence of a promising model of community collaboration to develop appropriate interventions to improve the informational needs of Latino families raising children with autism.

### **Critical analysis of the Socio-cultural Framework for Health Service Disparities applied to Latino children with autism and their families**

The Socio-cultural framework of health care disparities argues that disadvantage accumulates among racial/ethnic minority groups as a result of interactions of factors at the micro, meso, and macro levels across treatment systems and communities. Here the conflux of factors that relate specifically to Latino children with autism and their families as they relate to family burden and treatment access and utilization have been reviewed. The SCF-HCD model has been extended with the addition of several factors across the micro, meso, and macro levels.

A critical analysis of the reviewed literature sets the stage for the two studies included in this dissertation.

Alegría et al. (2011) propose that the factors across the micro, meso, and macro levels of Latino children and families span both the health care systems domain and the community systems. It is the combination of the factors along with the linking of the domains via mechanisms which produce cumulative disadvantage. Disparities in health services outcomes surface as a consequence of the cumulative disadvantage and negatively affect the impact of autism on the family. Furthermore, mismatched provider/clinician micro level factors within the health care systems domains in conjunction with the child and parent factors exacerbate poor clinical encounters that hinder access to and utilization of appropriate treatment services and burden the family. For Latino children with autism, the disparities manifest the unavailability of appropriate culturally-informed treatment and greater family burden.

In its present form, the socio-cultural framework for health service disparities does not include child or parent specific factors. This review highlights the interactions between child and caregiver factors. However, more research is needed to disentangle the specific mechanisms that are fueled by child and parent factors to produce cumulative disadvantage for Latino children with autism to treatment services and reduce family burden. Study 1 in this dissertation attempts to isolate such factors to understand the impact of autism on Latino family well-being, adjustment, and burden. In addition, the study provides a more detailed overview of family burden, how it fits into the SCF-HSD, and reasons for it to be considered in the context of autism and culture.

This chapter proposes that child and caregiver factors interact with clinician/provider micro factors including provider gender, race, and ethnicity, limited cultural competency training and



resources, bias attitudes towards and perceptions of clients, and use of guideline concordance care to produce poor clinical encounters. The research available on health care disparities among Latino children and autism specific research on racial/ethnic minorities suggests that poor clinical encounters experienced by parents give rise to disengagement with services.

At the meso level, Alegría et al. suggests the operation of community systems and social networks sectors with the operation of health care systems and provider organizations foster restricted pathways to and of care. Restricted pathways to and of care comprise a mixture of pathways into care for children and families, unsatisfactory interactions between families and providers, and mismatch in service offerings for Latinos. Latino children with autism interface multiple health care systems and provider organizations, including health, mental health, educational, and social service systems. Prior research indicates that these systems are ill prepared to manage the service needs of Latino children and families. The operation of community systems and social network sectors intersects with the health care systems and provider organizations via the perceptions of the health care system within the community, previous health care experiences by members of the community, and the sharing of information of community members about health care providers and health issues. Study 2 below summarizes many of these care issues that affect Latinos and incorporates them into a culturally-informed model of care for families of Latino children with autism. More specifically, the study utilizes Bernal's Ecological Validity Model (Bernal, Bonilla, & Bellido, 1995) that outlines an eight-dimensional framework of adaptations, including but not limited to language, client-therapist cultural backgrounds and relationship, and the inclusion of cultural metaphors in treatment, for interventions to enhance their ecological validity within the Latino population.

### **Limitations of the available literature**

Several limitations in the available research pertaining to child health disparities among Latino children and more specifically Latino children with autism, were found and warrant further research. For instance, recruitment and retention strategies have been unclear and negligent in targeting Latino children for inclusion in autism related studies, there is a scarcity of information available about Latino subgroups children and families in such work, absence of policy driven studies, theoretical frameworks in papers focused on racial/ethnic minorities and autism, and limited information about effective practices with Latino families. The limitations contribute to the weaknesses in understanding the complexities of Latino children with autism and their families and the absence of interventions designed to increase access to treatment and participation among Latino children with autism.

The present methods of recruitment and retention used in autism research have not afforded comprehensive samples of Latino children and families. Very few have included Latino participants at the child and/or parent levels. A study by Thomas, Ellis, McLaurin, Daniels, & Morrissey (2007) aimed to identify factors related to access of services for families coping with autism. The study included families who opted to participate in the study. Families were selected based on their use of existing ASD services or connection to them in their community. This method of sampling, may have overestimated the use of services compared to the general ASD population and left out families who did not have knowledge of autism symptomology, those with less understanding of the service systems available to them, and those with compromised time. Moreover, children not yet diagnosed but who do have autism, children misdiagnosed, and children of immigrant status or living in extreme poverty may not be included in the national databases that many autism studies are based on. The researchers acknowledged that these concerns are particularly relevant to children and families from racial/ethnic minority

backgrounds. Such recruitment methods are similar across many studies on autism. Parent report varies by awareness and understanding of autism. Parent report of autism among Latinos is significantly lower than white and other traditionally underrepresented families. Thus, Latinos are at a significant risk for exclusion from autism- related studies. Study 1 and Study 2 in this dissertation include culturally-informed strategies to recruit and retain Latino families in research. The successful recruitment and retention rates in the studies suggest it is possible to design studies that deliberately recruit and retain Latino<sup>6</sup> children with autism and their families. It would be valuable for larger scale studies to employ these methods in order to obtain adequate samples of ethnic sub-groups.

In recognition of the National Research Council's (2001) suggestion to recruit children and families of diverse backgrounds in autism research, several studies have attempted to recruit populations of color. However, the field is relatively new to ethnic group considerations and cultural diversity. The most recent studies that report variation in sample characteristics have grouped together different ethnic groups. Researchers have used overarching labels such as "Latino/Hispanic" and/or grouped all non-White participants into a "racial/ethnic minority" group or the "other" category. Possible confounding variables related to the diversity within the groups have not been explained and leave much room for interpretation of findings.

Findings from studies that have included more representative samples of Latinos suggest differences in the way cultural groups experience raising a child with ASD (Blacher & McIntyre, 2006; Magaña & Smith, 2006). For some families, who perceive the disability as stigmatizing may challenge service accessibility and utilization, while for others, the perception of health providers as discriminatory or culturally insensitive limits treatment advocacy (Surgeon General, 2001). Other families may choose not to seek services as they view their child's disability as a

spiritual opportunity, gift, or test of faith (Klinger, Blanchett, & Harry, 2007). The variation demonstrates the need to assess autism across Latino subgroups.

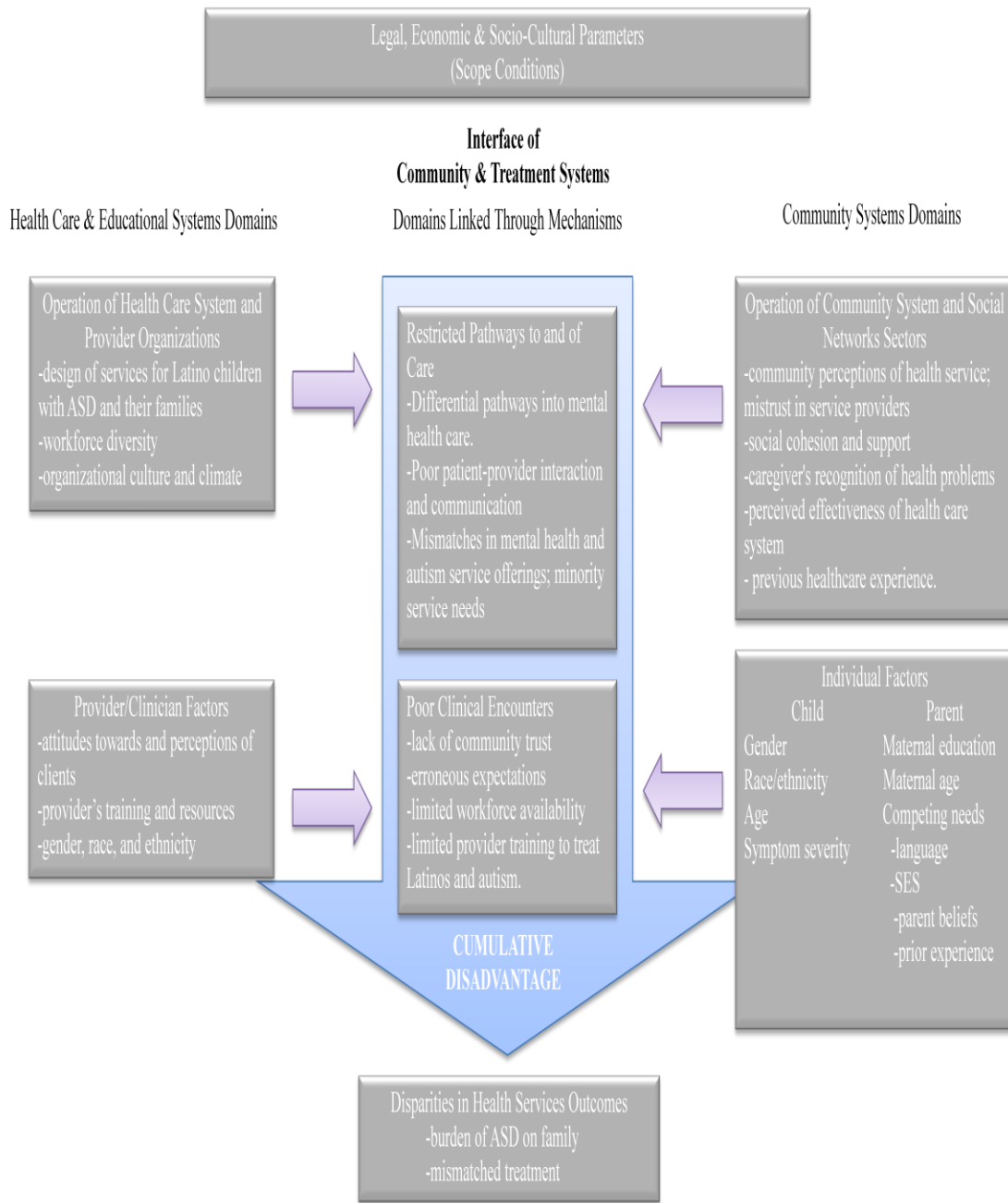
Recruitment and retention of racial/ethnic minority children in longitudinal and intervention studies on autism are abysmal. There is a significant disparity in longitudinal studies of qualitative changes in symptoms and/or intervention efficacy for Latino children from racial/ethnic minority groups. The majority of publications that have incorporated these children are case studies of individual children (Lakes, Lopez, & Garro, 2006). Case studies provide important qualitative data that large scale quantitative studies do not emphasize. However, a sample size of one or very few children greatly limits the generalizability of findings. In addition, children from certain ethnic groups, such as Latinos, have barriers to attending intervention programs developed for families with moderate amounts of resources. It is evident that the available research limits the application of the SCF-HSD framework on the experiences of Latino families with autism and treatment services over time.

The themes related to the inclusion of populations of color in the present research on disparities in autism diagnosis and service utilization are only a glimpse of the issues that limit study with Latino children with autism. The SCF-HSD framework offers several hypotheses to disentangle the conflux of factors affecting Latino children with autism and their families. However, the available research on Latino children with autism and their families is not sufficient to test the majority of the hypotheses posited by the SCF-HSD framework. Multiple concerns must be addressed in theory construction, study design, recruitment, data analyses, and the interpretation of findings to enhance the framework. Efforts will rely on the innovative and culturally informed strategies and goals of researchers, funding capacity, and resources. Training for researchers in these domains is imperative for the progress of work on autism

among Latinos, development and implementation of appropriate treatment, and the increase of service utilization.

## **Conclusion**

Latino children with autism and their families encounter disproportionate factors that limit intellectual knowledge about their experiences and limited access to and utilization of intervention. Using the Socio-cultural Framework for Health Service Disparities the disparities are defined as a social injustice to Latino children and families in this chapter. Further, the factors that produce cumulative disadvantage prevent understanding the Latino family experience and limit the development of culturally-informed interventions for Latino children with autism and their families were explored. The SCF-HSD was expanded to include child and parent factors, as well as relevant autism-related outcomes such as family burden. A modified conceptual model that includes variables at the micro and meso levels is provided (See Figure 2.1). The modified model offers several new hypotheses for researchers to explore in an effort to expand the understanding of Latino families raising children with autism, inform the development of culturally-informed policies and care, and reduce disparities. The next two chapters isolate factors from the modified conceptual model and use data to empirically explore their relevancy.



**Figure 2.1. Modified Socio-cultural Framework for Health Service Disparities**

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## Chapter III

### Family Burden among Latino Families with Children on the Autism Spectrum

The prevalence of autism spectrum disorders (ASD) has increased dramatically over the past two decades. The Centers for Disease Control (CDC; 2013) estimates that one in every 88 children is affected by ASD. Thus, a growing number of families are or will be impacted by ASD. Previous findings indicate raising a child with autism is associated with a host of negative consequences including high financial costs (Kogan, Strickland, Blumberg, Singh, Perrin, & van Dyck, 2008), decreased employment (Cidav, Marcus, & Mandell, 2012), negative maternal well-being (Ekas, Lickenbrock, & Whitman, 2010), higher rates of depression among mothers (Blacher & McIntyre, 2006), and increased family stress (Bouma & Schweitzer, 1990; Dabrowska & Pisula, 2010). For instance, Bouma and Schweitzer (1990) researched the experience of mothers of children with cystic fibrosis, autism, and no disability. They found mothers of children with autism reported higher levels of family stress compared to the other mothers. Similarly, Blacher and McIntyre (2006) found parents of young adults with autism reported the lowest level of maternal well-being compared to caregivers of children with intellectual impairment, cerebral palsy, and Down's syndrome.

While caregiver burden and well-being has been reviewed heavily in the literature, there is limited work on the impact of autism on family well-being and adjustment, otherwise known as *family burden*. Moreover, the experiences raising a child with autism have not been explored in families from a variety of racial/ethnic backgrounds. Dyches, Wilder, Sudweeks, Obiakor, and Algozzine (2004) suggest that the experience of raising a child with autism may vary by race,

ethnicity, and culture. Research evidence identifying unique challenges of family burden among racial / ethnic minorities will promote relevant interventions to enhance appropriate care.

The purpose of this study is to enhance the understanding of family burden among Latinos raising children with autism by utilizing an emerging theory on health care service utilization. In addition, the study expands recent research that suggests that having a child with a disability may actually enhance parents' sense of the family's well-being and cohesion. The specific aims include exploring whether or not there are differences in pessimism and family burden among Latina and non-Latina mothers, investigating the separate dimensions of family well-being and functioning as well as negative burden, and disentangling sociodemographic and sociocultural factors that affect pessimism and family experience. Although there is no research available about pessimism and family burden among Latino families of children with autism, a review of the literature available about Latino families and autism, pessimism and family burden among Latino families, pessimism, burden and autism, followed by emerging research on the positive impact among caregivers of children with intellectual disabilities is provided. Lastly, the available research is incorporated into the Sociocultural Framework for Health Service Disparities which is proposed here to have the potential to guide these unexplored areas of research.

### **Latino Children with Autism and Families**

A growing number of children are diagnosed with autism, yet Latinos are distinctly underrepresented in autism research (Magaña, Lopez, Aguinaga, & Horton, in press). Latino children are more likely to be diagnosed with autism at a later age and receive fewer services compared to White children (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Latino parents report less knowledge about ASD and utilize fewer services compared to non-Latino White

families (Magaña, Lopez, Aguinaga, & Horton, in press). Additionally, Latino children and families face numerous challenges including poverty, language barriers, limited education, and restricted access to health care (Flores, Abreu, & Kastner, 1998). These competing sociodemographic challenges will further complicate the experience of raising a child with autism. The compounding effects will have adverse effects on service access and utilization which affect child outcomes and family burden. It is imperative to explore variables affecting family burden among Latinos raising children with autism in order to develop and implement services that meet their specific needs. Identifying factors that reduce family burden will be particularly important to incorporate into intervention protocols.

### **Pessimism, Family Burden and Mental Illness among Latinos**

Familism, defined as strong feelings of loyalty, reciprocity, and solidarity among family members (Marin & Marin, 1991) as well as family support and one's obligations to the family, is a central value within the Latino culture (Sabogal, Marin, Otero-Sabogal, Marin, and Perez-Stable, 1987). Magaña and Smith (2006) suggest that familism may lead to differences in perceptions of the burden associated with a family member's disability. Specifically, they argue that one's obligations to the family may enhance the acceptance of a family member's disability and buffer the negative impact of the disability among Latinos.

Other research has demonstrated that the conceptualization of disability among Hispanics affects their perception of burden and pessimism about their child's future. For instance, research by Jenkins (1988) on the conceptualization of schizophrenia in Hispanic families suggests that Hispanic families conceptualize mental illness along a continuum whereby they accept the disability as well as maintain hope for the future. Jenkins and Schumacher (1999) suggested that the acceptance and hope for the future may be associated with decreased family burden. In



addition, their hope for the future implies that Latinos may have low levels of pessimism about their child's future in the presence of disability. This work suggests that current measures of the disability impact might overemphasize negative impacts and overlook positive outcomes associated with having a family member with autism in Latino families. The available research on Latino families of children with autism does not include analyses distinguishing family well-being and functioning from family burden nor has pessimism been explored. Finally, the possible mediating effects of the importance of family among Latinos on pessimism and family burden warrant investigation.

### **Pessimism among Caregivers of Children with Autism**

Pessimism about the child's future has been shown to be associated with a host of adverse caregiver and child outcomes among families of children with autism spectrum disorders. Increased pessimism about the child's future has been linked to high levels of depression, maternal criticism, and increased caregiver strain among mothers of children with ASD (Abbeduto et al., 2004). Conversely, low levels of pessimism was found to contribute to more positive parent-child relationships characterized by positive affect, expressed emotion, and maternal warmth, among children with autism and their caregivers (Orsmond, Seltzer, Greenberg, & Krauss, 2006). Finally, Lin (2012) found reduced functional independence and increased severity of autism predicted higher levels of pessimism in a sample of Taiwanese mothers of adolescents with ASD. The results of the studies demonstrate the relation among maternal and child factors and pessimism. Absent from the literature is an examination of pessimism about their child's future among Latino families. Based on work identifying Latinos hope for the future in the face of mental illness it is possible that Latino families have low levels of pessimism in contrast to other caregivers of children with autism. Understanding the role of

pessimism within Latino families may facilitate the design of practice approaches for working with these families.

### **Burden among Caregivers of Children with Autism**

Multiple autism-related studies have found caregivers of children with autism have elevated stress levels and are at increased risk for depression. A consistent finding in work on caregiver stress, burden, and/wellbeing among caregivers of children with autism is the impact of child behavior problems. The research indicates that a greater number of child behavior problems is related to elevated stress and burden levels. For example, LeCavalier, Leone, and Wiltz (2006) found that increased conduct problems were associated with greater caregiver stress over time among caregivers of young people with autism. Similarly, Blacher and McIntyre (2006) as well as Bishop, Richler, Cain, and Lord (2007) found higher perceived negative impact of autism was associated with more child behavior problems. In a ten year longitudinal study of parents of children with autism Gray (2002) found high levels of stress among parents of aggressive and/or violent children. The amount of time associated with caring for a child with autism has also been found to be associated with lower levels of maternal well-being (Sawyer, Bittman, La Greca, Crettenden, Harchak, & Martin, 2010).

Finally, Dabrowska and Pisula (2010) found levels of maternal education and styles of coping to impact parenting stress among caregivers of children with autism. In particular, they found higher educated mothers and mothers who adopted more emotion-oriented coping strategies also reported increased stress. The research on caregiver burden demonstrates several sociodemographic and sociocultural factors across the child and caregiver levels that may also be associated with the impact of autism on families. Caregiver burden research appears to provide a

foundation for exploring family burden and may facilitate the integration of appropriate methods of treatment for families of children with autism.

### **Emerging Research on Raising Children with Intellectual and Developmental Disabilities**

While there is limited research on the positive experience of raising a child with autism, there is growing literature on the positive impact of raising a child with developmental disabilities. For instance, Blacher and Baker (2007) disentangled three distinct views of positive impact that have saturated the literature on caregiver burden and children with developmental disabilities. The three views include the “low negative”, “common benefits”, and “special benefits” views. The “low negative” view defines positive impact as low scores on measure of adverse well-being. The “common benefits” view implies parents raising a child with a disability undergo the same positive experiences as parents of children without disabilities. Lastly, the “special benefits” view proposes raising a child with a disability offers benefits over and above that of raising a child without a disability. The two part study included 282 young adults, ages 16-26, with intellectual disability and 214 children, ages 3-5, with or without developmental delays. Approximately 50% of both samples were Latino and 50% were non-Latino White children and parents. Blacher and Baker found differences in negative and positive experiences among Latino and White families. Specially, Latina mothers reported higher levels of positive impact compared to non-Latino White caregivers. Positive impact or well-being was not inferred from low scores of negative impact (i.e., the “low negative” view). These findings did not support the “low negative” view and suggests measures of negative impact should not be used as a substitute for measuring positive impact. Instead, the study results supported the “common benefits” view. Specifically, responses on the positive impact measure did not differ among parents of non-delayed and delayed children, implying the “common benefits” view applied to

the sample. The variation observed in negative and positive impact evidences the need to investigate both experiences of caregivers raising children with ASD. The study offers a starting point to consider the range of experiences among families of children with developmental disabilities. The findings suggest that Latino caregivers may be more likely to view having a child with a disability as ultimately positive for their families' well-being. Furthermore, although the previous work on Latino families raising children with developmental disability emphasizes an overall negative experience, Latino families may have positive experiences that will only be uncovered with the appropriate measures of both negative and positive impact.

Additionally, it is critical to measure both positive and negative experiences raising a child with a developmental disability because the different experiences may affect caregiver well-being and overall family experience. For instance, Trute, Hiebert-Murphy, and Levine (2007) interviewed 103 families of children with intellectual and developmental disabilities. The interviews included the Family Impact of Childhood Disability scale (FICD; Trute & Heibert-Murphy, 2002), a 15-item assessment of positive and negative appraisals of the family impact of childhood disability. Caregivers were also given the Rosenberg Self-Esteem scale (RSE; Rosenberg, 1965) to measure caregiver self-esteem and the Family Assessment Measure III – Brief Form (FAM\_BF; Skinner, Steinhauer, & Santa-Barbara, 1983, 1995) to assess family organization and functioning. Families were interviewed six months following their child's entrance into childhood disability services (Time 1), and one year later (Time 2). On average, children were four years of age at Time 1. At Time 1 caregivers reported both positive and negative appraisals of their experience with their children. Mothers' positive appraisal at Time 1 predicted mothers' self-esteem and early family adjustment at Time 2. No differences were found for negative appraisals. Consistent with Blacher and Baker, the Trute et al. study suggests it is

important to disentangle both caregiver positive and negative appraisals in assessing overall family experience. Although the study sheds light on the differential impact the two types of appraisals have on caregiver well-being and overall family experience, the results are limited to non-Latino White families.

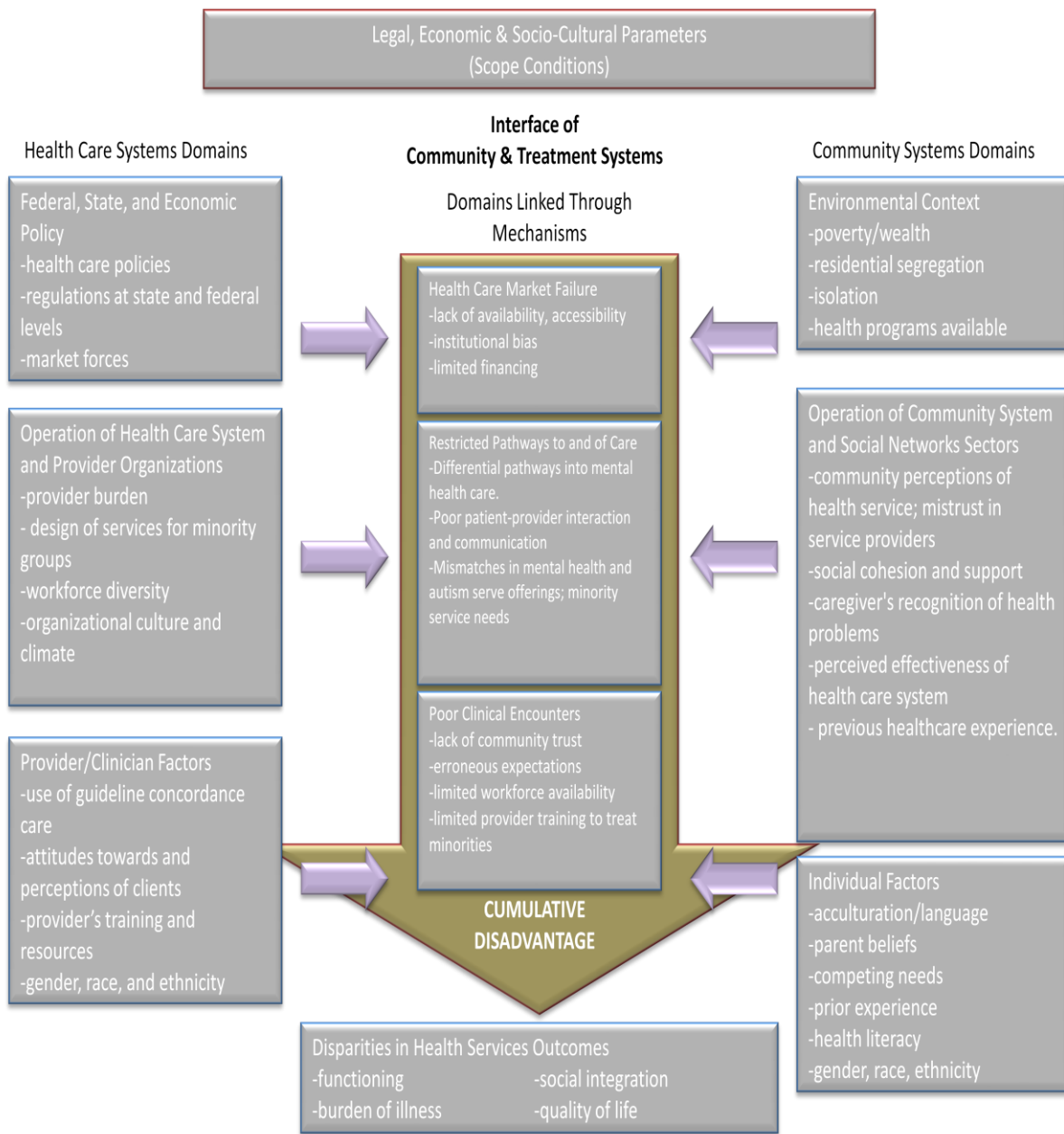
In light of emerging research on family experience raising children with developmental disabilities, there remain several gaps in understanding the family impact of autism. As mentioned above very little is understood about how to conceptualize the impact of autism among Latino families. Only one study to date has explored the impact of autism on Latino caregivers. Magaña and Smith (2006) explored caregiver well-being and distress among Latino mothers living with their youth or young adults with autism. All mothers were interviewed in their homes as part of a larger study and sent self-administered questionnaires to gather data for this study. Depressive symptoms were measured with the Center for Epidemiologic Studies Depression Scale (CES-D, Radloff, 1977), mood states with the Profile of Mood States (McNair, Lorr, & Droppleman, 1981), and questions about purpose in life, self-acceptance, and environmental mastery were from Ryff's (1989) psychological well-being measure. The researchers found Latina mothers reported less distress and more well-being compared to non-Latina White mothers. Mothers were also asked two open-ended questions inquiring about the positive and negative things about living with their child with autism. Both groups emphasized family closeness and the family as the most natural context for their child. Latina mothers were less likely than non-Latina White mothers to express negative views of coresidence with their child. The findings run counter to the overwhelming number of studies reporting the negative impact of autism on caregivers. The findings suggest that Latina mothers raising children with autism may experience less burden than non-Latina White mothers and emphasize the

importance of family cohesion among families. While a promising study that contextualizes the impact of autism on Latinos the study is limited to the impact of autism on caregiver well-being. There remains a dearth of information available about Latino *family* well-being and functioning and family burden among those raising children with autism.

Lastly, although a number of factors have been found to affect caregiver experience and family impact among other racial/ethnic groups, there are no complex models of the relationships among child, caregiver, and family factors within Latino families. A summary of research findings supports a careful exploration of components of family burden and well-being among Latino families. Additionally, an application of a culturally specific framework of health care disparities will advance the understanding of Latino families of children with autism. In the next section I outline the Sociocultural Framework for Health Services Disparities which I use to guide the review of factors I propose may affect family well-being and burden among Latinos with children on the autism spectrum.

### **Socio-cultural Framework for Health Service Disparities**

Alegría, Pescolido, Williams, and Canino's (2011) socio-cultural framework for health service disparities (SCF-HSD) suggests disparities in health are a function of multiplex disadvantage that involves culture, the individual, service systems and community (see Figure 2.1 for model). The framework was designed to aid the development of research on Latinos and mental health service utilization. In the original model Alegría et al. speak to disparities regarding functioning, social integration, burden of illness, and quality of life. Alegría et al. draw the proposition that racial/ethnic groups have community and treatment system experiences and routines at each stage of managing health and illness problems which fuel health disparities. According to the SCF-HSD model, disparities over the illness career are a function of multiplex



*Figure 3.1. Socio-cultural Framework for Health Services Disparities*

disadvantage involving the individual, service system and community. Furthermore, the points for intervention according to the SCF-HSD include the interaction points between community and treatment. The interaction points are broken down to three levels of analysis, the micro level (individual; provider or patient), meso level (organizational; formal organizations or lay sectors), and the macro level (societal; larger policy or environmental contexts). The community and health care system function at each of the three levels.

In the context of autism, it is appropriate to further extend the model by considering the impact of the disorder on family burden as a potential health disparity. Additionally, broadening Alegria's model to include the impact of child, family, and social support factors at the individual level of the community system will contribute to the conceptualization of family burden among families raising children with autism across Latino and non-Latino White families. The model is especially useful as a starting point for the current study because it considers a host of factors across the micro, meso, and macro levels that affect Latino families.

According to the SCF-HSD the perceived impact of raising a child with autism is one of a host of factors across the micro, meso and macro levels that may contribute to service utilization. Specifically, the experience of raising a child with autism operates at the micro level of the SCF-HSD. Given that the experience raising a child with autism may affect the manner in which Latino families seek and/or utilize services it is critical to investigate their experience to inform the development and implementation of treatment and outreach services for Latinos. In this study the framework is utilized to contextualize family burden of autism among Latinos and non-Latino White families of children with autism and provide a modified model (see Figure 3.2). The modified model fills the gaps in current research that does not provide a context for the



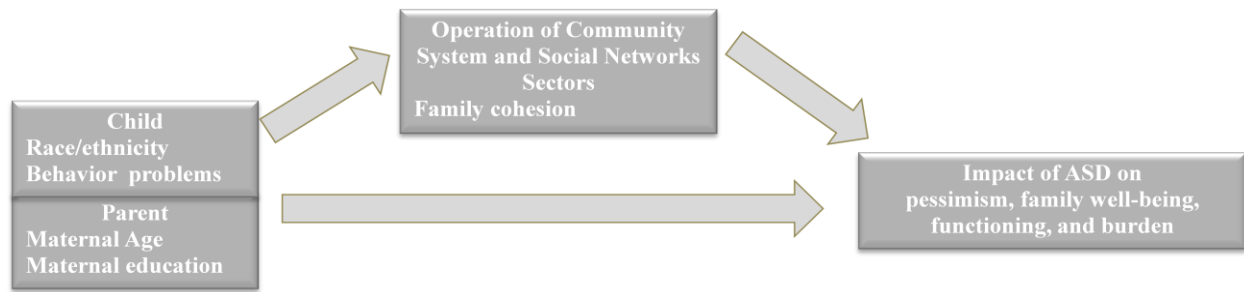


Figure 3.2. Family Impact Conceptual Model

experiences of Latinos raising children with autism and provides a tool to develop and test hypotheses that may affect their experiences and disparities. Next, the more specific conceptual model featured in Figure 3.2 for Latino children with autism and their families is outlined.

In the SCF-HSD child characteristics such as behavior problems, operate at the micro level of the community system. Child behavior problems have consistently been shown to impact families of children with autism. For instance, Blacher and McIntyre (2006) found caregivers of 282 young adults with autism reported more maladaptive behavior problems and lower personal well-being compared to caregivers of children with intellectual impairment and cerebral palsy. The researchers noted the number of behavior problems more strongly predicted negative impact than did child’s diagnosis. The results indicate measures of child behavior problems should be included when investigating family impact and mother well-being.

Family cohesion is nested in the meso level within the SCF-HSD as social network sectors. The degree to which families are cohesive may influence diagnostic and treatment service utilization for their children with autism. As mentioned previously, Latinos tend to rely heavily on family for social support (Bailey et al., 1999; Carter-Pokras & Zambrana, 2001). Moreover, family cohesion, or the *emotional bonding that family members have toward one another* (Olson, Porter, & Bell, 1982) has been found to mediate the relationship between

problem behavior and family burden among Latina mothers of children with intellectual disability (Magaña, Schwartz, Rubert, & Szapocznik, 2006). These findings suggest that family cohesion may influence the impact of autism on families and should be analyzed as a potential mediator.

Utilizing the SCF-HSD to explore the impact of autism on children and families across racial/ethnic backgrounds may help to illuminate how the different experiences associated with disparities in family burden. This study is a first step to disentangling the complicated SCF-HSD model to isolate relevant factors that contribute to pessimism, family well-being, functioning, and burden. Understanding the perceived impact of autism on Latino families may aid in the development of culturally informed services that enhance service utilization among families, reduces burden, and develops family strengths.

**Hypotheses** It is expected that Latina mothers report less pessimism and family burden than White mothers. Second, Latina mothers are expected to endorse positive experiences with their children at a higher rate than White mothers. Third, family cohesion is expected to mediate the relation between ethnicity and pessimism. Fourth, family cohesion is expected to mediate the relation between ethnicity and family burden. Last, it is hypothesized that child ethnicity, behavior problems, maternal education, maternal age, and family cohesion will predict levels pessimism and family burden.

## **Methods**

### **Participants and Procedure**

Latina and non-Latina White families were recruited with the help of service agencies, support groups and organizations that provide services or advocacy for children with developmental disabilities and their families in a Midwest state. Inclusion criteria were that the

mother was the main caregiver, and the child had a diagnosis of an ASD and was between the ages of 2 and 22 years old. ASD diagnosis was determined by asking the caregiver if they had ever been told their child had an autism spectrum disorder.

Child age at the time of the study ranged from 2 to 21 years of age ( $\mu=9.46$ ;  $SD=4.45$ ). Latina mothers were interviewed in their homes about treatment and services, parental stress and coping, and autism symptoms among their child with autism. Bilingual, bicultural interviewers conducted the interview in the language of preference of the caregivers. Seven Latina mothers chose to have the survey conducted in Spanish. Measures that were not previously translated to Spanish were translated via translation/back translation with committee review and

A total of 54 Latina mothers were interviewed. Forty-five Latina mothers who completed the full interview are included in the present study. A group of non-Latina White mothers were asked to complete the treatment and services questionnaire as a mail survey. Participants were recruited through targeted email on organizational listservs (e.g. Autism Society), and through service agency mail outs. Eighty eight non-Latina White mothers of children with ASD expressed interest in the study. Sixty-one completed the questionnaire. Fifty-six of these mothers reported their race/ethnicity as White, four mothers reported their race/ethnicity as Asian and one reported herself as being Latina/Hispanic. Due to the small N of mothers of Asian descent, they were excluded from the analysis. The mother who reported being Latina/Hispanic was included in the Latino group. The final sample included a total of 56 non-Latina White mothers and 46 Latina mothers.

Differences in demographic characteristics between the two groups are shown in Table 3.1. The majority of children were male in both groups. White mothers reported significantly more behavior problems ( $M=4.88$ ,  $SD=1.91$ ) among their children compared to Latina mothers

( $M=3.91$ ,  $SD=2.12$ ),  $t(102)=-2.41$ ,  $p<.05$ . White mothers, on average, were older ( $M=43.89$ ,  $SD=6.62$ ) than Latina mothers ( $M=38.22$ ,  $SD=8.80$ ),  $t(102)=-3.65$ ,  $p<.001$ . Most Latina mothers (84.8%) were born in Latin America and the average number of years they had lived in the US was 13.59 ( $SD=7.75$ ), ranging from 1 to 38. Latina mothers reported less education, with most completing a high school diploma or less (56.6%), compared to White mothers who primarily reported obtaining a college degree (71.4%),  $X^2=38.42$ ,  $p<.001$ . The vast majority of White mothers (80%) reported incomes of \$50,000 or more, while the majority of Latina mothers (56.5%) had incomes ranging from 0 to \$29,000,  $X^2=42.11$ ,  $p<.001$ . Lastly, more White mothers (92.9%) than Latinas (67.4%) were married or lived with their partner,  $X^2=10.81$ ,  $p<.01$ .

## Measures

### Child Factors

**Child's diagnostic group** was determined by parent report. Mothers were asked whether their child had ever received a diagnosis of autism, Asperger's syndrome, or PDD-NOS. Follow-up questions inquired about who gave the diagnosis and the current status of the diagnostic label. Latino parents were also administered the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) as part of a larger study. *Child's age* at the time of the interview was collected along with child's *gender*.

**The number of behavior problems** was measured using the Scales of Independent Behavior Revised (SIB-R; Bruininks Woodcock, Weatherman, & Hill, 1996). The SIB-R provides a comprehensive assessment of 14 areas of adaptive behavior and 8 areas of problem or maladaptive behavior. The SIB-R is a norm-referenced measure. Mothers were asked whether their child exhibited any of the maladaptive behaviors and responses were coded (1) yes, (0) no. Values of 1 were summed to compute the total number of child behavior problems. According to the manual, test-retest reliability for the SIB-R is .86 and Chronbach's alpha is .80. The SIB-R

was previously translated in Spanish and has been used in studies of Latino populations (Blacher & McIntyre, 2006).

### **Maternal Factors**

Maternal demographic variables were included in the first portion of the interview and survey. The demographics included in this study are *maternal age, place of birth, number of years in the US, family income, education, employment and marital status*.

**Pessimism** was measured by the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983). The QRS-F is a 52-item self-administered, true/false tool that measures parental perceptions of the impact of a developmentally delayed or chronically ill child on other family members. The QRS-F consists of four subscales that assess parental perceptions. The subscales include parent and family problems, pessimism, child characteristics, and physical incapacity. The QRS has been found to have high reliability and construct validity (Holroyd, 1988). The English and previously translated Spanish version of the scale by Magaña et al. (2006) were used in this study. Ten items that comprise pessimism focus on parents' pessimistic beliefs about the child's future. The alpha reliability for the pessimism scale ranged .70 to .72 in previous work (Orsmond, Seltzer, Greenberg, & Krauss, 2006; Abedduto et al., 2004). Sample items include, "I have accepted the fact that my son or daughter might have to live out his/her life in some special setting (such as a group home)" and "I am disappointed that son or daughter does not lead a normal life". Higher scores indicate greater pessimism regarding specific worries about the future for their child with ASD. The mean for the current sample was 5.60 ( $SD=2.15$ ) and scores ranged 1 to 10. Internal reliability was .64.

### **Family Factors**

**Total family burden** A revised version of the Parent and Family Problems subscale in the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983) was used to measure family burden. The revised version excludes five items from the original subscale that focus on global psychological distress not relevant to a measure of family specific burden. The revised version was originally used by Glidden and Floyd (1997) and was found to have adequate reliability. The fifteen items assess caregiver burden and family well-being and functioning. Parents are asked to note whether the statement is true or false for them. Sample items include, “Given up things I wanted to care for my son or daughter” and “The family does as many things together now as we ever did” (reverse coded). Responses are summed for a total burden score with higher scores indicating higher levels of burden on families. The mean for the entire sample was 6.89 ( $SD=3.98$ ). Chronbach’s alpha coefficient for the current study is .81.

**Family well-being and functioning** Six positively worded items from the family burden scale were summed to create a measure of *family well-being and functioning*. The six items included, “Our family agrees on important matters”, “My son/daughter is able to fit into the family social group.”, “I can go visit with friends whenever I want.”, “The family does as many things together now as we ever did.”, “There are many places where we can enjoy ourselves as a family when my son/daughter comes along.”, and “Members of our family get to do the same kinds of things other families do.” A higher score on the scale indicates greater family well-being and functioning. The mean for the entire sample was 3.58( $SD=1.69$ ). Chronbach’s alpha for the family well-being and functioning scale in this study is .71.

**Negative family burden** The nine burden items that are worded negatively were summed to measure negative family burden. The nine items included, “Other members of the family have to do without things because of my son/daughter.”, “The constant demands for care for my

son/daughter limit growth and development of someone else in our family.”, “I have given up things I have really wanted to do in order to care for my son/daughter.”, “In the future, our family’s social life will suffer because of increased responsibilities and financial stress.”, “Taking my son/daughter on vacation spoils pleasure for the whole family.”, “There is a lot of anger and resentment in our family.”, “The constant demand to care for my son/daughter limit my growth and development.”, “I often worry about what will happen to my son/daughter when I no longer can take care of him/her.”, and “Caring for my son/daughter puts a strain on me.”. Higher scores are indicative of greater negative family burden. The mean for the entire sample was 4.53( $SD=2.74$ ). The internal reliability for the negative family burden scale is .71.

**Family cohesion** was assessed with the subscale of the Family Adaptation and Cohesion Scale II (FACESII; Olson, Porter, & Bell, 1982). The subscale was previously translated into Spanish by Martinez-Pampliega et al. (2006) and found to have suitable reliability of .89. Ten items measured family cohesion. Examples of these items are, “Family members like to spend free time with each other”, “Family members feel very close to each other”; and “Family togetherness is very important.” Possible responses to each item were 3 = strongly agree, 2 = somewhat agree, 1 = somewhat disagree, and 0 = strongly disagree. Responses were summed for a total family cohesion score ranging 5 to 30. The overall mean was 24.66( $SD=6.07$ ). Higher scores indicate stronger family cohesion. The internal reliability for the current study is .94.

Table 3.1

Demographic Characteristics

Child	Latino (n=46)		White (n=56)		X <sup>2</sup> or t
	Mean or Percentage	SD	Mean or Percentage	SD	
Age	9.13	4.20	9.73	4.66	-0.67
Gender					0.65
female	24.4%		17.86%		
male	75.6%		82.14%		
missing					
# of Behavior Problems	3.91	2.12	4.88	1.91	-2.41*
Maternal					
Age	38.22	8.80	43.89	6.62	-3.65***
Birth Place					
Latin America	84.8%				
United States	13%				
missing	2.2%				
Years in the US <sup>1</sup>	13.59	7.75			
Education level					38.42***
less than HS	28.3%		--		
HS	28.3%		5.4%		
Some college	23.9%		23.2%		
College	19.6%		71.4%		
Income					42.11***
0-\$29,000	56.5%		5.5%		
\$30,000-49,999	21.7%		14.5%		
\$50,000 and higher	19.6%		80%		
missing	2.2%		--		
Employed	52.2%		66.1%		2.03
Married or living with partner	67.4%		92.9%		10.81**

<sup>1</sup>Years in the US is based on the 39 participants who were born outside the US.

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$



## Results

Table 3.2 indicates the means, standard deviations, and t-test results comparing Latina to non-Latina White mothers on the outcome measures, pessimism, family burden, family well-being and functioning item scale, negative family burden item scale, as well as the proposed mediator, family cohesion. T-tests showed that Latina mothers reported lower levels of pessimism ( $M=5.11$ ,  $SD=2.06$ ) than White mothers ( $M=6.01$ ,  $SD=2.17$ ) and Latina mothers reported lower levels of family burden ( $M=5.35$ ,  $SD=3.88$ ) compared to White mothers ( $M=8.16$ ,  $SD=3.63$ ),  $t(100)=-3.77, p<.001$ . The positively worded items were then separated from the negatively worded items and summed for two subscales, family well-being and functioning and negative family burden. T-tests were performed to identify differences in the levels of family well-being and functioning and negative burden between the two groups. Latina and non-Latina White mothers differed significantly on family well-being and functioning, with Latina mothers averaging  $4.30(SD=1.56)$  and non-Latina White mothers having a mean of  $2.98(SD=1.61)$ ,  $t(100) = 4.25, p = .000$ . In addition, higher levels of negative family burden were reported by non-Latina White mothers  $5.31(SD =2.44)$  compared to Latina mothers  $3.65 (SD=2.83)$ ,  $t(100)=-3.05, p<.01$ .

To examine the hypotheses that family cohesion would mediate the relation between ethnicity and pessimism as well as mediate the relation between ethnicity and family burden the statistical technique described by Baron and Kenny (1986) was used. The technique requires a series of three regressions to show 1) the independent variable X (ethnicity) affects a mediator M (family cohesion) that in turn affects the dependent variable Y (pessimism or family burden). However, there was no significant difference found between ethnicity and family cohesion. Therefore, the mediation model was not supported for either of the outcomes.

In order to address the hypothesis that child factors (ethnicity, behavior problems), maternal factors (maternal age, maternal education), and family factors (family cohesion) would affect levels of pessimism and family burden two hierarchical regression models were developed for pessimism, total family burden, family well-being and functioning, and negative family burden. Model 1 included ethnicity, behavior problems, maternal age, and maternal education. Model 2 included the proposed mediator, family cohesion. Prior to performing the hierarchical multiple regressions the independent variables were examined for collinearity. All independent variables had a collinearity tolerance of .53 or greater. Thus, the estimated  $\beta$ s are well established in the regression models. Additionally, analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity.

Table 3.4 provides the results for Models 1 and 2 for pessimism. Model 1 for pessimism accounted for 10% of the variance (adjusted  $R^2$ ) and was significantly different from zero,  $F_{(4,97)}=3.79, p<.05$ . A positive relationship between maternal age and pessimism was found,  $\beta = .306, p<.01$ . In Model 2 family cohesion was added to the analyses. Model 2 increased the proportion of variance accounted for to 19.5%,  $F_{(5,97)}=5.89, p<.001$ . After adding family cohesion, maternal age remained a significant predictor of pessimism,  $\beta = .283, p<.01$ . The proposed mediator, family cohesion was also found to be a significant predictor of pessimism,  $\beta = -.320, p<.01$ .

For the second outcome variable, total family burden, table 3.5 displays Model 1 and 2 results. Model 1 which included ethnicity, behavior problems, maternal age, and maternal education, explained 23.7% of the variance (adjusted  $R^2$ ) and was statistically significant,  $F_{(4,97)}=8.84, p<.001$ . The number of child behavior problems,  $\beta = .183, p<.05$ , maternal age,  $\beta = .220, p<.05$ , and maternal education,  $\beta = .280, p<.05$ , were positively related to family burden.

After including family cohesion in Model 2 39.1% of the variance (adjusted  $R^2$ ) in the model was accounted for,  $F_{(5, 96)}=13.98$ ,  $p<.001$ . The number of behavior problems remained a significant predictor of family burden with family cohesion included,  $\beta = 0.183$ ,  $p<.05$ . Additionally, maternal age,  $\beta = 0.191$ ,  $p<.05$ , maternal education,  $\beta = 0.272$ ,  $p<.05$ , and family cohesion,  $\beta = -.398$ ,  $p<.001$  significantly predicted family burden.

To identify what variables predicted the positively worded items (family well-being and functioning) and negatively worded items (negative family burden) that compose the total family burden scale separate hierarchical multiple regressions were performed on 6 positively worded items and 9 negatively worded items. Table 3.6 displays Model 1 and 2 results for family well-being and adjustment. Model 1 which included ethnicity, behavior problems, maternal age, and maternal education, explained 20.4% of the variance (adjusted  $R^2$ ) and was statistically significant,  $F_{(4, 97)}=7.49$ ,  $p<.001$ . Negative relationships between maternal age and family well-being and functioning was found,  $\beta = -.230$ ,  $p<.05$ . With the addition of family cohesion in Model 2, the amount of variance (adjusted  $R^2$ ) accounted for increased to 37.2%,  $F_{(5, 96)}=12.98$ ,  $p<.001$ . In model 2, maternal age remained a significant predictor of family well-being and functioning,  $\beta = -.200$ ,  $p<.05$  and family cohesion emerged as a predictor as well,  $\beta = .415$ ,  $p<.001$ .

For negative family burden, model 1 accounted for 21.8% of the variance (adjusted  $R^2$ ) and was statistically significant,  $F_{(4, 97)}=8.05$ ,  $p<.001$  (see Table 2.7). The number of child behavior problems,  $\beta = .297$ ,  $p<.01$ , maternal age,  $\beta = .195$ ,  $p<.05$ , and maternal education,  $\beta = -.287$ ,  $p<.05$ , were found to have a positive relationship with the negative item scale. When the proposed mediator, family cohesion, was added in Model 2 31.2% of the variance was explained,  $F_{(5, 96)}=10.16$ ,  $p<.001$ . Maternal age was no longer significant after family cohesion was added.

However, the number of child behavior problems,  $\beta = .254$ ,  $p < .01$  and maternal education,  $\beta = .281$ ,  $p < .05$  remained predictors. Lastly, family cohesion was found to have a negative relationship with negative family burden,  $\beta = -.316$ ,  $p < .001$ .

Table 3.2

Means, standard deviations, and t-tests for outcome variables and mediator

	<b>Latinas</b>		<b>Whites</b>		<b>t</b>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Pessimism mother-imputed	5.12	2.06	6.01	2.17	2.14*
Total Family Burden	5.35	3.88	8.16	3.63	3.77***
Family Well-Being and Functioning items	4.30	1.56	2.98	1.61	-4.11***
Negative Family Burden items	3.65	2.83	5.31	2.44	3.11**
Family Cohesion	25.22	5.80	24.20	6.29	-0.85

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Table 3.3

*Bivariate Correlations among Independent Variables*

	1	2	3	4
1. Behavior Problem	1			
2. Maternal Age	.01	1		
3. Maternal Education	.13	.27*	1	
4. Family Cohesion	-.14	-.09	-.07	1

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Table 3.4

*Hierarchical Multiple Regression for Pessimism*

	<i>B</i>	<i>SE B</i>	$\beta$
Model 1			
Latino	-.33	.54	-.08
Behavior Problems	-.05	.10	-.05
Maternal Age**	.08	.03	.31
Maternal Education	.13	.24	.07
Model 2			
Latino	-.31	.51	-.07
Behavior Problems	-.10	.10	-.09
Maternal Age**	.08	.03	.28
Maternal Education	.12	.23	.06
Family Cohesion**	-.11	.03	-.32

Model 1, *adjusted R*<sup>2</sup>=.100\*; Model 2, *adjusted R*<sup>2</sup>=.195\*\*\*

\**p*<.05 \*\**p*<.01

Table 3.5

*Hierarchical Multiple Regression for Total Family Burden*

	<i>B</i>	<i>SE B</i>	$\beta$
Model 1			
Latino	-.41	.92	-.05
Behavior Problems*	.46	.17	-.24
Maternal Age*	.11	.05	.22
Maternal Education*	1.04	.41	.28
Model 2			
Latino	-.36	.82	-.05
Behavior Problems*	.36	.16	.18
Maternal Age*	.09	.04	.19
Maternal Education*	1.01	.37	.27
Family Cohesion***	-.26	.05	-.40

Model 1, *adjusted R*<sup>2</sup>=.237\*; Model 2, *adjusted R*<sup>2</sup>=.391\*\*\*

\**p*<.05 \*\**p*<.01 \*\*\**p*<.001



Table 3.6

*Hierarchical Multiple Regression for Family Well-being and Functioning*

	<i>B</i>	<i>SE B</i>	$\beta$
Model 1			
Latino	.56	.40	.17
Behavior Problems	-.08	.08	-.10
Maternal Age*	-.05	.02	-.23
Maternal Education	-.32	.18	-.20
Model 2			
Latino	.54	.36	.16
Behavior Problems	-.04	.07	-.05
Maternal Age*	-.04	.02	-.20
Maternal Education	-.31	.16	-.19
Family Cohesion***	.12	.02	.42

Model 1, *adjusted R*<sup>2</sup>=.204\*\*\*; Model 2, *adjusted R*<sup>2</sup>=.372\*\*\*

\**p*<.05 \*\**p*<.01 \*\*\**p*<.001

Table 3.7

*Hierarchical Multiple Regression for Negative Family Burden*

	<i>B</i>	<i>SE B</i>	$\beta$
Model 1			
Latino	.11	.64	.02
Behavior Problems**	.40	.12	.30
Maternal Age*	.07	.03	.20
Maternal Education*	.73	.28	.29
Model 2			
Latino	.14	.60	.03
Behavior Problems**	.34	.12	.25
Maternal Age	.06	.03	.17
Maternal Education*	.72	.27	.28
Family Cohesion***	-.14	.04	-.32

Model 1, *adjusted R*<sup>2</sup>=.218\*\*\*; Model 2, *adjusted R*<sup>2</sup>=.312\*\*\*

\**p*<.05 \*\**p*<.01 \*\*\**p*<.001

## Discussion

The purpose of this study was to advance the understanding of pessimism and family experience with autism among Latinos by utilizing the sociocultural framework for health service disparities (SCF-HSD). The specific aims included identifying differences in total family burden between Latina and non-Latina White mothers, separately investigating the positive (family well-being and functioning) and negative (negative family burden) impact of having a child with autism, and disentangling sociodemographic and sociocultural factors that affect family experience. Additionally, the perceived impact of autism on total family burden, family well-being and functioning, and negative family burden from caregiver pessimistic beliefs about their child's future was distinguished by assessing a measure of mother reported pessimism.

For the first hypothesis it was expected that Latina and White mothers would report lower levels of total family burden. In line with the hypothesis, the findings indicated that Latina mothers reported lower levels of overall family burden compared with White mothers. The results contradict previous research on Latina mothers raising children with disabilities or intellectual impairment whereby Latina mother reported higher levels of burden compared with White mothers (Magaña, Seltzer, & Krauss, 2004; Magaña, Schwartz, Rubert, & Szapocznik, 2006). However, the findings are supported by Magaña and Smith (2006) who found Latina mothers reported less distress and greater satisfaction with the coresidence of their child with autism.

The findings may reflect differences in the manner in which Latina mothers conceptualize autism. For example, previous work using the same sample of mothers by Lopez, Magaña, Cross, Paradiso, and Piper (2013) found that the Latina mothers were more likely than non-Latina White mothers to report their child's autism was a test, challenge, or blessing from

God compared to non-Latina White mothers. Their child's autism might serve as a source of hope and support for Latinas that enables them to reframe negative perceptions (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). This hypothesis is further supported by Jenkins (1988) work on the conceptualization of schizophrenia in Hispanic families indicating that Hispanic families conceptualization of mental illness incorporates both acceptance of the disability and hope for the future.

The findings are also reflected by the work of Dyches, Wilder, Sudweeks, Obiakor, & Algozzine (2004) who underscored the variation in adaptation to stressors in multicultural families with low socioeconomic status. Dyches et al. suggested the Resiliency Model of Family Stress, Adjustment, and Adaptation accounts for the differences and addresses issues of ethnicity and culture in the adaptation of multicultural families with low socioeconomic status. It "emphasizes the family's appraisal processes involving ethnicity and culture that facilitate the family's ability to institute new patterns of functioning and achieve harmony while promoting the well-being and development of its members" (McCubbin, McCubbin, Thompson, & Thompson, 1998, p. 5). The model's purpose is that families go through two phases, adjustment and adaptation. Adjustment includes stressors or a "demand placed on the family that produces, or has the potential of producing, changes in the family system" (p. 6). Stressors can be either positive or negative. Stressors range in severity on a continuum of how much they disrupt the family unit, or add demands on the family, depleting the resources and capabilities. Appraisal is then defined as "the family's definition of the seriousness of a stressor and its related hardships" (p. 6). Negative (e.g., some Navajos are reported to believe that the child's autism may be the fault of the parents or a result of witchcraft) and positive appraisals (e.g., some young Latino mothers accept the child as a blessing or gift from God) may be the result of the family's

interpretation of the etiology of the child's disabilities. Other research indicates that Latina mothers are less aware of autism information (Magaña, Lopez, Aguinaga, & Horton, in press), which may shape their well-being and burden perceptions. It is possible that Latina mothers' decreased awareness serves as a protective factor against perceptions of negative outcomes.

Second, Latina mothers were expected to endorse positive experiences with their children at a higher rate than White mothers. Latina and non-Latina mothers were found to vary on eleven family burden questions. Two patterns in the differences emerged, with a higher percentage of Latina mothers endorsing the positively worded items (family well-being and functioning) compared to White mothers and more White mothers endorsing negatively worded items than Latina mothers. For the positively worded items, Latina mothers were more likely to endorse four items including *"My son/daughter is able to fit into the family social group"*, *"I can go visit with friends whenever I want"*, *"The family does as many things together now as I ever did"*, and *"Members of our family get to do the same kinds of things other families do"*. The results suggest that the Latina mothers in this study perceive their children with autism to be integrated into their daily lives more so than White mothers. According to Chavira, Lopez, Blacher, and Shapiro (2000) it is probable that Latina mothers attribute less responsibility for behavior problems to their children with disabilities. Attributing less responsibility may enhance the integration of their children into family life and reduce their perceived burden of autism on the family. Lastly, even in the absence of disability, Latino parents have been found to value close, warm, and supportive relationships with their children (Cuilamo-Ramos, Dittus, Jaccard, Johansson, Bouris, & Acosta, 2007; Vega, 1990). Such values may have enabled the Latina mothers to dissuade the burden of their child's autism and incorporate them into the family context.

The second trend in item differences found was that White mothers scored higher on questions negatively worded items (negative family burden). The specific items they differed on were, *“Other members of the family have to do without things because of my son/daughter”*, *“The constant demands for care for my son/daughter limit growth and development of someone else in our family”*, *“I have given up things I have really wanted to do in order to care for my son/daughter”*, *“The constant demand to care for my son/daughter limit my growth and development”*, and *“Caring for my son/daughter puts a strain on me”*. The differences suggest that White mothers feel more burden from their child’s autism than do Latina mothers. It is possible that their reports of more burden are due to the constraints their child’s autism has on their abilities to utilize their advanced education. Given that a high percentage of White mothers had a college degree or more, they may feel captive to their child’s autism, needs, and services. In order to further assess this assumption, it will be helpful to assess the impact of the number of services used on family burden in future research. Moreover, White mothers who have higher levels of education may also be more aware of the number of services available for their children. The time spent managing care and the cost of multiple services may further burden them. For instance, McManus et al. (2011) found that time obligations had a substantial influence on caregiver burden among parents of children with developmental disabilities. McManus et al. suggest that parents of children with disabilities have higher burden due to overseeing their children’s care, scheduling appointments with health and educational professionals, and advocating on their child’s behalf. According to Green (2007) their role as an informal caregiver places them in “double jeopardy” as they attempt to simultaneously balance their family, civic, and social responsibilities.

Lastly, child ethnicity, behavior problems, maternal education, maternal age, and family cohesion were hypothesized to predict levels of pessimism and total family burden. Higher levels of pessimism were reported by White mothers compared to Latinas and increased maternal age predicted higher levels of pessimism. Increased family cohesion predicted lower levels of pessimism. Contrary to prior research, child behavior problems did not impact mother-reported pessimism in this sample. The pessimism findings are consistent with earlier work showing mothers of children with autism report elevated pessimism levels (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). The lower levels of pessimism reported by Latina mothers may be a reflection of Jenkins' (1988) work indicating that Latinos have high hopes for the future regardless of disability. On the other hand, the reduced pessimism among Latina mothers may also be linked to lower levels of knowledge about the disability which may guard them against thinking about the possible long term effects of ASD on their child's future. The difference in Latina mothers report suggests more research to disentangle the perceptions of Latina mothers about their children's futures as well as their conceptualization of autism.

For total family burden the results indicated a higher number of behavior problems, increased maternal age, higher maternal education, and lower family cohesion predicted greater family burden. These findings confirmed previous research that the impact of autism on families is dependent on multiple factors (Bishop, Richler, Cain, and Lord, 2007; Blacher & Baker, 2007; Blacher and McIntyre, 2006). The results also support the proposed conceptual model rooted in the socio-cultural framework of health service disparities. In this study, children's level of behavior problems was found to have a positive relationship with family burden. These findings mimic previous studies that indicate children's behavior impacts caregiver well-being with more behavior problems having a negative effect on burden (Blacher & McIntire, 2006). Positive

relationships between maternal age and maternal education and overall family burden were also found. The results for maternal factors supported the work of Dabrowska and Pisula (2010) who also found higher maternal education to be related to higher levels of stress among parents of children with autism. It is especially important to highlight, that although ethnicity was expected to impact overall family burden, it was not a significant predictor of overall family burden with the inclusion of the other child, caregiver, and family factors. In particular, the inclusion of maternal education eliminated the significance of being Latino on family burden. The results highlight the importance of including sociodemographic factors in the investigation of family burden among families of children with autism. The findings suggest utilizing a socio-cultural lens to explore the Latino families with children on the spectrum. A socio-cultural framework would allow for the inclusion of factors across levels of the family unit as well as interactions among the factors.

To further investigate the impact of the child, caregiver, and family factors on burden the predictors were modeled on the positively worded items (family well-being and functioning) and negatively worded items (negative family burden) separately. Evaluating the models on different outcomes revealed there were differences in what variables predicted well-being and adjustment vs. burden. After dividing the positively worded items into a single family well-being and functioning scale maternal age and family cohesion emerged as predictors. Higher maternal age predicted less well-being and adjustment, whereas higher levels of family cohesion predicted more well-being and functioning. When determining the predictors of the negatively worded items (negative family burden) child behavior problems, maternal education, and family cohesion were found to be predictors. More child behavior problems, higher levels of maternal education, and less family cohesion were related to higher levels of negative family burden. The



variation in what factors predicted well-being and functioning compared to negative family burden further suggests the experience of raising a child is multifaceted. The findings support previous research on the utility of measuring positive and negative appraisals of raising a child with a developmental disability (Trute, Hiebert-Murphy, & Levine, 2007). Although the mediation model was not supported, the proposed conceptual model was partially validated given that child, caregiver, and family factors affected family well-being and functioning as well as negative family burden.

Family cohesion or the *emotional bonding that family members have toward one another* (Olson, Porter, & Bell, 1982) largely contributed to every model on family burden and pessimism for Latino and White families. These findings reinforce previous work that found family cohesion to influence family burden among Latina mothers of children with intellectual disability (Magaña, Schwartz, Rubert, & Szapocznik, 2006) as well as work on the impact of family cohesion on Latino family stress (Behnke, MacDermid, Coltrane, Duffy, & Widaman, 2008). These findings suggest that family cohesion and support may influence the impact of autism on families and should be included in models of family burden, well-being and adjustment, and pessimism. Consistent with the sociocultural framework of health care service disparities, social cohesion and support contributed to family burden, well-being and adjustment. The results stress the importance of utilizing a family systems approach when working with children on the spectrum and their families. Incorporating multiple family members into the context of treatment and helping them develop strategies to enhance their bond has the potential to reduce family burden, increase well-being and adjustment, and reduce maternal pessimism.

### **Limitations and Future Research**

The limitations of the study include the small convenience sample which limits the generalizability of the results. First, the Latino group was predominately born outside of the United States, of Mexican or Puerto Rican descent, had limited income and education attainment, and resided in an ethnic enclave. Although the sociodemographic characteristics of the group were representative of Latinos in other research the results do not generalize to all Latinos. Second, it appears that higher income White families with college degrees were more likely to participate. However, when income was included as a predictor in preliminary analyses, it did not predict pessimism or family burden suggesting that income does not account for the differences in pessimism and family burden between the Latinos and Whites in this sample. The relation between maternal education and family burden highlight the need to include White mothers with lower levels of education. To achieve more broadly applicable results, future research should include more participants of varied socio-economic backgrounds residing in diverse geographical locations. This will enable researchers to determine the impact of other variables more clearly. Fourth, the cross-sectional nature of the data does not allow for interpreting the directionality of the results. Moreover, the data collection procedures were different for the two groups of mothers. Latina mothers were interviewed in their homes and their preferred language. White mothers were mailed the same questions, but in a survey format. The different procedures may have affected mothers' openness in their responses. For instance, the Latina mothers may have felt pressured to respond positively by being interviewed in person about sensitive information regarding the experiences with their children.

It would also be helpful to use qualitative interviews to investigate how Latinos conceptualize and experience autism in their families. Understanding how Latina mothers cope with their child's autism and the relationship of their coping strategies to burden may help to fill

the gap in understanding why Latina mothers of children with autism reported lower levels of family burden. Finally, further exploration of the sociocultural framework of healthcare service disparities as it applies to family burden among Latino caregivers of children with autism is warranted. The framework was partially validated in this study, yet there are several proposed hypotheses that necessitate future research. For example, it will be valuable to investigate the impact of previous healthcare experiences, current treatment models, provider/clinician factors, and other relevant sociodemographic factors on family burden. By understanding the complexity of factors we will have a broader vision of what to include in models of care for children with autism and their families.

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## Chapter IV.

### **Feasibility of a Culturally Informed Intervention for Latino Children with Autism**

Autism is a developmental disorder characterized by qualitative impairment in social interactions, verbal and nonverbal communication, and the presence of restricted and repetitive behaviors. The prevalence of autism spectrum disorders (ASD) has increased dramatically over the past two decades. The Centers for Disease Control (CDC, 2012) estimates that one in every 88 children are affected by ASD. According to the CDC, between 2002 and 2008 ASD diagnoses increased 110% among Hispanic children. The observed increase was the greatest among all racial/ethnic groups. Outreach efforts, increased awareness and improved diagnostic tools have contributed to the growing numbers of Latino children diagnosed with autism. Despite the exponential increase there are no interventions and treatments developed for use with Latino children on the spectrum and their families. It is imperative to adapt or develop interventions for use with Latinos to mitigate adverse child and family outcomes as well as enhance access to appropriate care (Mandell & Novak, 2005). The purpose of this study is to introduce and test the feasibility of a culturally informed model of intervention, *Addressing the Informational Needs of Latino Immigrant Parents of Children on the Autism Spectrum*. This paper begins with a synopsis of autism intervention work and critique the absence of Latinos in such work, review research on culturally adapted interventions for Latino parents, describe the Ecological Validity framework that serves as the foundation for the model of intervention and identify how the proposed intervention fits the cultural adaptations suggested by the framework. Second, pre and post test data are compared to assess the feasibility of the intervention among Latino parents of

children with ASD. The guiding research question is, *How does a culturally-informed model of autism intervention affect knowledge of ASD and services among Latino families?*

### **Autism Intervention**

In an effort to enhance the representation of children with autism from a variety of sociodemographic backgrounds and increase the utility of interventions the Interagency Autism Coordinating Committee (IACC; 2011) strategic plan specified that, “Studies should include factors relating to the clinical practice, availability, and collaboration among community-based services, and information needs of parents, other caregivers, and early educators” (p.11).

Although multiple interventions have been developed for children with autism and their families they are based on several criteria that have not afforded the inclusion of Latino families and their unique needs. For instance, recruitment and retention strategies have been unclear and negligent in targeting Latino children for inclusion in autism related studies. No autism interventions are grounded in theoretical frameworks that address the unique experiences of Latino families. The studies that have included Latinos are limited to epidemiological work on age of diagnosis and service receipt. For example, a study by Thomas, Ellis, McLaurin, Daniels, & Morrissey (2007) aimed to identify factors related to access of services for families coping with autism. Families who participated were selected based on their use of existing ASD services or connection to them in their community. This method of sampling may have overestimated the use of services compared to the general ASD population and left out Latino families who are more likely to have limited knowledge of autism symptomology, less understanding of the service systems available to them, and multiple competing demands that reduce service use (Magaña, Lopez, Aguinaga, & Morton, in press). Moreover, there is a dearth of knowledge available about effective practices with the Latino population.

The intervention described here, *Addressing the Informational Needs of Latino Immigrant Parents of Children on the Autism Spectrum*, is grounded in previous research and fills several research gaps. First, it is designed to fulfill the informational needs about autism, services, and ways to work with their children reported by Latino families. Second, the intervention is guided by a culturally sensitive intervention framework developed to enhance the ecological validity of treatment for Latinos by modifying the development and delivery of treatment. This is the first use of the Ecological Validity framework to create an autism intervention.

Given that there are no published studies about the adaptation of autism intervention for use with Latinos or research on the proposed intervention, this study is focused on the feasibility of the intervention. The primary concern of this study is the feasibility of implementation, which constitutes whether the intervention can be executed in a clinical or community context utilizing pre-post data to compare outcomes before and after the intervention (Bowen et al., 2009). Thus, this study is focused on specific parent outcomes targeted by the intervention content. According to Bowen et al. although randomized control trails are the gold standard to determine the effectiveness of interventions, feasibility are important and necessary. Feasibility studies yield results that demonstrate the fit of interventions in real-world settings. This study will add to the autism intervention discourse early evidence of the feasibility of a culturally informed, community centered, and cost-effective intervention for Latino families. Last, the feasibility of the intervention to improve caregiver knowledge about autism, services and strategies to work with their children will offer insight to social workers about the unique considerations that must be taken into account in developing effective practices with Latino families with children on the autism spectrum.

## **Culturally Adapted Interventions with Latino Families**

Alegría, Atkins, Farmer, Slaton, and Stelk, (2010) emphasized the need for attention to diversity, culture, and context at the individual, family and organizational levels within mental health systems. The authors accentuate the impact that culture has on the reporting of symptoms, service use, and treatment dropout. Culture is "...developed interactively and is contextually defined." (pg. 51). Culture comprises an array of individual characteristics and experiences. McCubbin et al. (1993) echoed this hypothesis in their study of Latino families of children with chronic illnesses and disabilities. McCubbin et al. found culture to impact reactions to disability, beliefs in treatment, and decisions to seek treatment. Snowden, Hu, and Jerrel (1995) posit that culturally responsive interventions may increase service utilization. According to Organista (2007) the optimal model of Latino-focused programs should include culturally and socially competent practice imbedded in the technology, personnel, and structures of programs. Likewise, Guarnaccia & Rodriguez (1996) suggest culturally informed mental health treatment entails particular considerations that include adaptations of language, atmosphere, material signs and symbols, events and celebrations, shared values and views of mental illness.

Multiple conceptual models for adapting interventions with Latino parents have been proposed by researchers. For instance, Bernal's Ecological Validity Model (Bernal, Bonilla, & Bellido, 1995) outline an eight-dimensional framework of adaptations for interventions to enhance their ecological validity within the Latino population. The Ecological Validity Framework (Bernal, Bonilla, & Bellido, 1995) was developed to provide a culturally sensitive framing of treatment outcome research. The framework serves as a foundation to adapt or develop culturally sensitive treatment or interventions. According to Bernal and colleagues, culture, meaning, and context are critical elements to consider in the development of treatment

and interventions for Latinos. Further, they emphasize the role of *language, persons, metaphors, content, concepts, goals, methods, and context* in the adaptation of interventions for Latinos. *Language* refers to the language in which the intervention is developed, available, and delivered. *Persons* comprise the patient and therapist characteristics and the dynamic between them that make up the therapy relationship. The *metaphors* dimension includes symbols and concepts shared by the target population. *Content* refers to cultural knowledge including values, costumes, and traditions. The *concepts* dimension highlights the need for treatment concepts to be aligned with culture and context. *Goals* assume that the goals of treatment are not only developed jointly by the client and therapist, but also culturally appropriate. The seventh dimension, *methods* is defined as the procedures for achieving treatment goals. Last, the *context* dimension emphasizes the impact of context on participants (i.e., acculturative stress) and multiple contexts throughout the course of intervention such as the social context of the intervention. The framework suggests that including each of these dimensions in treatment or interventions for populations of color will improve the ecological validity as well as the external validity of the work. The framework offers an innovative structure to develop autism interventions for Latino families who have not been a focus in this area of research although they are a rapidly growing group of families affected by ASD.

Interventions inclusive of some or all of these elements developed for use with Latino caregivers have been found to decrease parenting stress (Borrego, Anhalt, Terao, Vargas, & Urquiza, 2006), improve parenting practices (Matos, Torres, Santiago, Jurado, & Rodriguez, 2006) and have the potential to increase parenting self-efficacy and lessen caregiving burden (Magaña, 2006). For example, Martinez & Eddy (2005) designed a parent management training for Spanish-speaking Latino families. The culturally specific adaptations included bilingual

Latino staff and culturally relevant topics (i.e., strong Latino roots, multiple family roles). The intervention was found to improve parents' overall effective parenting and decrease the likelihood of youth using substances, aggression, and other externalizing behaviors. While Martinez and Eddy's adapted intervention as well as others for Latino parents has shown gains in parenting and child outcomes the interventions are limited in scope. The scope of the interventions has included only low-income, urban, and/or single parent households, or children/youth with aggressive behaviors and/or conduct problems. No culturally adapted interventions have included Latino children with autism and their families. Next, I review the barriers to intervention involvement and how the proposed intervention fills the gaps for Latinos in this study.

### **Latino Children with Autism and Families**

Latino children and families face numerous challenges including poverty, language barriers, limited education, and restricted access to health care (Flores, Abreu, Olivar, & Kastner, 1998; Alegría et al., 2007). The compounding effects may have adverse effects on service access and utilization as well as child outcomes among Latino children with autism. Research on utilization of services among Latinos with autism indicates that Latinos are less likely than whites and other racial/ethnic minorities to have access to services and a limited number of Latinos utilize services (Liptak et al., 2008; Parish, Magaña, Rose, Timberlake, & Swaine, 2012). A study on Latino and White families raising children with autism spectrum disorders by Magaña, Lopez, Aguinaga, and Morton (in press) found Latino parents had limited sources of knowledge about autism and were often unaware of the availability of treatment services in comparison to non-Latino White families. Additionally, knowledge about autism contributed to the number of services their children received. The study suggests that increasing Latino

families' knowledge about autism and available services will contribute to service utilization. Bailey, Skinner, Correa, and Arcia (1999) used qualitative interviews with 200 Latino parents (Mexican and Puerto Rican couples) to identify a pattern of needs across informational and social support domains among parents caring for children with development disabilities. Latino parents reported they had limited information about their child's disability, information about services, and information about how to work with their children. Reduced English language proficiency was also linked to a greater need for family and social support and explaining to others and lower support from family and friends. This study suggests that Latino parents have limited knowledge about developmental disabilities and available services as well as reduced social support. Additionally, those who are limited in English proficiency have added constraints on their ability to access information and supports. Thus, interventions designed for use with Latino families should be offered in their language of preference and include strategies to enhance their knowledge about disability, services, social support.

In addition to language consistency and content of interventions, quality of services has been found to affect service utilization among Latinos with autism. According to Magaña, Parish, Rose, Timberlake, and Swaine (2012) Latino and Black children with autism have poorer quality of care compared to non-Latino White children. Using the National Survey of Children with Special Health Care Needs (NSCSHCN) data Magaña et al. found racial/ethnic differences in five of six health care quality indicators. Specifically, Latino parents were more likely than both Black and White parents to report they did not have a personal doctor or nurse, their child's doctor did not spend enough time with their child, their provider is not sensitive about their family values/customs, the doctor did not make them feel like a partner, and they did not receive enough information from their doctor. Parish et al. (2012) extended these results by assessing the

impact of the health care quality indicators on the utilization of services among Latino and White children with autism and other developmental disabilities in the NSCSHCN data. The results indicated that Latino children with autism and other developmental disabilities had diminished health care access, utilization, and quality compared to White children. Mediation analyses revealed health care quality mediates the relationship between ethnicity and health care utilization disparities. Specifically, time spent with provider, provider cultural sensitivity, and feeling of partnership with the provider mediated ethnicity and utilization.

These studies suggest that Latino families are in need of more autism related information, autism services, and greater quality of health care services. It is apparent that Latino families of children with autism encounter unique barriers to accessing interventions. Moreover, the available interventions are not culturally informed to meet their distinct needs. Next an innovative model of intervention was described to meet the informational needs of Latino families in a culturally informed manner.

### **Addressing the Informational Needs of Latino Immigrant Parents of Children on the Autism Spectrum Intervention**

The intervention, *Addressing the Informational Needs of Latino Immigrant Parents of Children on the Autism Spectrum* is based on the Ecological Validity Framework and serves as an innovative approach to recruit and retain Latino families in autism intervention programs. The intervention was designed specifically for Latino parents of children with autism. The intervention is a psycho-education based intervention that blends evidence-based practices for autism (i.e., Applied Behavior Analysis) with culturally informed practices to specifically meet the needs of Latino children and families affected by autism and their communities. The intervention is collaboration between the University of Wisconsin and Wisconsin Family



Assistance Center for Education, Training, and Support (WI FACETS). WI FACETS is a statewide non-profit organization, with its main office located in Milwaukee, Wisconsin. The mission of FACETS is "...to provide and broaden opportunities that enhance the quality of life for children and adults with disabilities and their families, with emphasis on support for underserved families in the community" (<http://www.wifacets.org/about-us.php>). WI FACETS serves a large proportion of Latino families.

For the current intervention, two intervention manuals and accompanying family handouts were developed by an advisory board composed of autism and community based research experts in addition to community members. Most of the members of the team were of Latino descent and/or had extensive experience working with the Latino community.

Module 1 titled, *Entendiendo el Autismo, Puedo Entender Mejor a Mi Hijo/a* [Understanding Autism, I Can Better Understand My Son/Daughter]. The module is comprised of information on child development, ASD diagnosis, understanding the child's behaviors, advocacy strategies, and explaining the child's behaviors to others. Module 2 called, *Padres en Accion: Estrategias Comprobadas para Apoyar el Aprendizaje de su Hijo/a* [Parents in Action: Proven Strategies for Supporting Your Child's Learning] includes strategies to improve child behaviors, communication, and social interaction.

In accordance with the Ecological Validity Framework the intervention includes the eight dimensions of adaptation. First, the previous research indicates autism interventions have only been developed and provided in English. This intervention addresses the *language* dimension of the framework by developing and implementing all sessions and activities to parents in Spanish making them accessible to Spanish-language speakers.

Second, the *persons* element which emphasizes the impact of ethnic or racial matching between clients and therapists was addressed by using promotoras de salud, or community health workers, to deliver the intervention content. The promotoras shared racial/ethnic identity and experience with the participants in that they were also Latina mothers of children with autism. The promotora model is a community collaborative approach that includes the use of community healthcare workers to inform and deliver culturally-informed intervention services. The promotora model has enhanced the recruitment of Latino participants in intervention studies and has shown improvement of health education and outcomes (WestRasmus, Pineda-Reyes, Tamez, & Westfall, 2012). Moreover, the promotora model has been found to be effective in providing information about child health and modifying parent behaviors to improve child health among Latino children (Ayala et al., 2010; Rhodes, Foley, Zometa, & Bloom, 2007).

Third, the *metaphors* dimension which includes concepts and symbols relevant to Latinos was met with the use of common Spanish sayings or “dichos” throughout the modules. The inclusion of Latino cultural values such as familismo and personalismo fulfilled the *content* dimension which comprises cultural values, history, and traditions. Parents’ perceptions of child development, disability, service systems and parent misconceptions about diagnosis and treatment of autism were included in the development and modification of the modules to enhance the *concepts* dimension which calls for culturally sensitive terms and concepts.

The framework dictates that the *goals* and *methods*, dimensions matched the cultural values and beliefs. Thus, *goals* were designed in conjunction with parents with the aim of developing their knowledge and treatment efficacy. The *methods* dimension paralleled Latino cultural values in that they included the Promotora de Salud Model which has been found to meet the cultural values of Latinos in other work and concentrates on relationship building,

flexibility as well as including the family. Additionally, radionovelas or sequential radio dramas that have been found to be popular among Latinos and useful as health education materials that reach and affect Latino parents (Kepka, Coronado, Rodriguez, & Thompson, 2011), were used to fulfill the methods dimension of the framework.

Finally, the *context* dimension which underscores clients' social context and the impact of changing contexts on clients, was addressed by working closely with a community-based organization which serves the Latino community, conducting sessions in each family's residence, including other family members in the intervention at the parents' discretion, and informing parents about resources in close proximity to them.

Addressing each dimension of the Ecological Validity Framework in the development and implementation of the intervention is the first and only culturally-informed intervention that meets multiple areas of need for Latino families raising children with autism. This study will add to the autism intervention discourse early evidence of the feasibility of a culturally informed, community centered, and cost-effective intervention designed for Latino families.

## **Hypotheses**

This study tests the feasibility of a culturally informed model of intervention for use with Latino families of children with autism. The differing information included in the two intervention modules, necessitate separate hypotheses for each module.

Module 1 expectations include: 1a) increases in caregiver understanding of their child's needs and strengths, knowledge of their rights, information about accessing their community, understanding how to help their child develop and learn, know-how about support system, 2a) increases in caregiver knowledge about autism symptoms, 3a) reduced maternal depression

levels, 4a) improvements in caregiver efficacy and satisfaction, and 5a) decreases in caregiver burden over time.

For Module 2 it is hypothesized that the intervention will lead to: 1b) increased caregiver confidence and satisfaction, 2b) reduced caregiver burden, and 3b) increased efficacy in using the intervention strategies and more use of the strategies.

## **Method**

### **Participants**

Latina primary caregivers of a child with autism were recruited to participate in each module. Participants were required to be Spanish speaking, first or second generation immigrant from Latin America, and the primary caregiver of a child with an ASD diagnosis between the ages of 2 and 8 years. Participants were recruited through the FACETS Spanish speaking support group. All participants were given the option to participate in one or both modules.

Twenty-one caregivers participated in module one. Three participants dropped out of the intervention. One participant dropped out after the first session. One left the study for undisclosed reasons. Two others dropped after the second session due to extensive family issues and time constraints. Thus, the retention rate for Module 1 was 86%. Data presented here are from the 18 mothers who completed both the pre- and post-tests for module one. The average age of children in module one was 5.76( $SD=1.64$ ). Over 90% of the children were male. Mothers averaged 33.17( $SD=6.20$ ) years of age. Eighty-three percent of mothers reported their ethnicity as Mexican/Mexican-American/Chicano, followed by 5.6% other Latino, 5.6% Puerto Rican, and 5.6% Latino/non-Latino. Sixteen module one participants participated in module two. Of the three participants who dropped out, one dropped after two sessions and two others after the first session. Reasons for leaving the study were not provided by the participants. This left

the retention rate at 81%. The mean age of the thirteen children who completed both the pre and posttests in module two was 6.15( $SD=1.95$ ). Children averaged 2.62( $SD=2.33$ ) behavior problems, as measured by the SIB-R. Mothers mean age was 33.62( $SD=6.86$ ) years. Ninety-two percent of the participants were Mexican/Mexican-American/Chicano and 7.7% Puerto Rican. The majority of mothers in both modules were born in Latin America. The average number of years mothers had been in the US was 12.41 ( $SD=4.45$ ) with a range of 4 to 25 years. The majority of mothers did not have a high school diploma, were unemployed, and were either married or living with a partner. Household incomes for most mothers were less than \$20,000 a year. See Table 4.1 for demographic characteristics of the sample.

**Design** Three promotoras were selected to deliver the content of the intervention. Promotoras were required to be the parent or family member of a child with an ASD of any age, be of Latin American descent, and fluent in Spanish. Promotoras received training on the intervention modules from the research and FACETS staff prior to delivering content to participants. The training for each module included two full days of reviewing the sessions in each module along with discussion and questions to clarify the content. Promotoras were given the same pre- and post-test measures at the beginning and end of training to assess their knowledge of the content.

Promotoras administered the informed consent and pre-tests during the initial in-home visit with caregivers. Seven sessions followed for a total of eight weekly intervention sessions. Each visit lasted approximately one hour. All participants in module one completed eight sessions. For module two, the average number of completed sessions was 6.54, with a range of 2-8 sessions completed. The post-test was administered during the eighth visit for each module. To track the feasibility of the intervention two feasibility measures were developed by the

research team. The *Participación y Cancelaciones (Participation and Cancellations)* feasibility measure served as an attendance sheet for sessions and documented the reason for cancelling. The *Actividades en Casa (Home Activities)* feasibility measure inquired about whether the participant completed homework for each session and promotora comments about the homework.

## **Measures**

**Module 1: Family Outcome Survey-Revised (FOS;** Bailey, Hebbeler, Olmstead, Raspa, & Bruder, 2008). The FOS is a 24 item self-report instrument designed to gather information on family's strengths and needs to support early intervention programs for children with disabilities and their families. The instrument contains 24 items that assess 5 family outcomes and 17 items which measure 3 program indicators. The FOS was previously translated and used in Spanish by Olmstead et al. (2010). Olmstead found two of the subscales to have Chronbach alphas ranging between .80 and .63 with a Spanish speaking sample. The five family outcome subscales, understanding your child's strengths, needs, and abilities; knowing your rights and advocating for your child; helping your child develop and learn; having support systems; accessing the community, were included in this study. Reliabilities for the individual scales at the pretest were .68, .85, .86, .87, and .86 respectively. At the post test the reliabilities were .41, .43, .91, .56, and .65. Internal reliability for the 24 family outcome items used in this study at pretest was .94 and .75 in the posttest.

**Knowledge about autism** was measured by the Maternal Autism Knowledge questionnaire developed by Kuhn and Carter (2006). The measure includes 41 true/false questions regarding facts about autism diagnosis and etiology, symptoms, treatments and interventions. Sample items included "Autism occurs in roughly equal numbers of boys and

girls.”, and “Many children with autism have trouble tolerating loud noises or certain types of touch.” The internal reliability of the scale at the pretest was .74. At the posttest the Chronbach’s alpha was .72.

**Caregiver burden, satisfaction and efficacy** are measured by a scale adapted by Heller, Miller, & Hsieh (1999) that has 20 items and three sub scales with response categories ranging from (1) strongly disagree to (3) strongly agree. The items were translated into Spanish and back translated by the study team. In a previous promotora project on Latina mothers of children with developmental disabilities the reliabilities for the subscales were .84, .73, and .79. Caregiver burden included nine items about the effects of caregiving for a child with autism on job opportunities, finances, future worry, personal time, social opportunities for leisure, and the caregiver's marriage. Chronbach’s alpha at the pretest was .88 and .81 during the posttest. Caregiver satisfaction includes five items about the caregiver-child relationship. For instance, “Helping my child makes me feel closer to him/her”. Chronbach’s alpha at the pretest was .89 and .67 during the posttest for caregiver satisfaction. Caregiver efficacy is comprised of six items based on Bandura's (1986) concept of self-efficacy. The items were developed to assess caregiver efficacy in parenting a child with a developmental disability. Sample items include, "I honestly believe I have the skills necessary to be a good caregiver to my relative" and "I can manage my child's behavior." In the current study the Chronbach’s alphas for the overall measure at the pretest was .85 and .64 during the posttest.

**Depressive symptoms** were measured with the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D consists of 20 items that rate the frequency of depressive symptoms over the last week. Possible responses ranged from (1) rarely to (4) most of the time. The CES-D was previously translated into Spanish by the developers and

is available to the public. Chronbach alpha reliabilities have ranged .88-.89 among caregivers of children with developmental disabilities (Magaña, 1999; Magaña & Smith, 2006). The Chronbach alpha in the present study at the pretest was .88 and .95 at the posttest.

Module two measures included *severity of autism symptoms, child behavior problems, caregiver burden, satisfaction and efficacy, use of intervention strategies, efficacy, and social validity* of the intervention strategies.

**Severity of autism symptoms** was measured by the Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1993). The ABC is a 57-item behavior rating scale with the ability to inform diagnosis of ASD by determining the probability of diagnosis in children. A pre-validated Spanish version of the ABC, the Inventario de Comportamientos Autísticos (ICA; Marteleto & Pedromônico, 2005), shown to have high specificity and sensitivity, was used. Five domains of behavior are included: sensory, relating, body concept, language, and social and self-help. Higher scores for each domain indicate elevated severity of symptoms. Higher total ABC scores indicate increased likelihood of ASD diagnosis. The internal reliability for the checklist in this sample was .78 in the pre-test and .86 in the posttest.

**Child problem behavior** was assessed by the Scales of Independent Behavior Revised (SIB-R; Bruininks et al., 1996). The SIB-R is comprised of 8 categories of behavior problems divided into 3 domains: internalizing, externalizing, and asocial behavior. The parent/caregiver rates the frequency and severity of the 8 behavior problems during the past 6 months. The internal reliabilities for the SIB-R have ranged .87-.96 in previous work (Lecavalier, Leone, & Wiltz, 2005). The SIB-R was previously translated into Spanish and used in studies of Latino populations (Blacher & McIntyre, 2006).



**Caregiver efficacy, burden, and satisfaction** were measured with the same items as used in module one. The internal reliability for caregiver efficacy in the pretest was .62 and the posttest was .73. For caregiver burden, the Chronbach's alpha was .83 in the pre-test and .63 in the posttest. Lastly, the internal reliability for caregiver satisfaction in the pretest was .56 and .63 in the posttest.

**Use of intervention strategies** was based on 14 items developed by the research team to assess how often caregivers used the intervention strategies targeted in module two. The items were translated and back translated by the research team. Responses ranged from 0) never to 3) always. Sample items include, "How often do you immediately reward your child for positive behaviors?" and "How often do you use modeling to show your child what you want him/her to do?" Higher scores indicate increased frequency of use. Chronbach's alpha for the pretest was .91 and .85 for the posttest.

**Efficacy** in using the intervention strategies was measured by 10 items created by the research team. The items were designed to assess caregiver efficacy to use the strategies taught in module 2. Sample items include, "I feel confident setting the stage for learning for my child" and "I understand the purpose of antecedents/behavior/consequences (ABC) chart". Possible responses include 0) strongly disagree to 3) strongly agree. Higher scores suggest higher levels of efficacy in using the strategies. The items were translated and back-translated by the study team. The internal reliability for the pre-test was .92 and .90 in the posttest.

The **social validity of intervention strategies** was developed for the present study. The measure is an 15-item, anonymous social validity questionnaire that assesses parents' perceptions regarding the acceptability and feasibility of intervention strategies, the effectiveness

of the intervention strategies in changing their child's behavior, and the applicability of the intervention strategies for use by other families. Response categories ranges from (1) strongly disagree to (6) strongly agree. Items were translated and back-translated by the research team. Social validity was assessed during the posttest of module 2. The internal reliability for the scale was .46.

## **Analyses**

Bivariate correlations were conducted on module one measures and module two measures to assess relationships. Paired t-tests were used to test for pre-post differences in the all module one and module two measures. Cohen's d was used to indicate effect sizes for each of the pre and posttest outcomes was calculated using Morris and DeShon's (2002) equation 8 which corrects for dependence between means.

## **Results**

Correlations for Module One pre-tests are provided in Table 4.2, for the posttest in Table 4.3, and the pre-test/posttest in Table 4.4. Paired t tests were used to compare outcome variables for module one and 11 outcome variables for module two. Analyses for Module One outcomes are illustrated in Table 4.5. To test hypothesis 1a, the subscales and overall score on pre and posttests from the Family Outcome Survey were analyzed. Increases in the family outcome survey subscales and the overall score from pre to posttest were observed. Specifically, Latina mothers reported that they had greater understanding of their child's needs and strengths over time,  $t(17)=8.68, p<.001$ , enhanced knowledge of their rights and how to advocate for their child,  $t(17)=5.99, p<.001$ , better information about how to help their child develop and learn,  $t(17)=4.51, p<.001$ , increased knowledge of support systems,  $t(17)=3.95, p<.01$ , and they had greater access to the community,  $t(17)=4.13, p<.01$ . Overall, Latina mothers' scores on the

Family Outcome Survey increased from pre to posttest,  $t(17)=6.56, p<.001$ . All effects sizes for the scale exceeded  $-1.01$ , suggesting large effects.

For hypothesis 2a concerning caregiver knowledge of autism, increases from pre to posttest were expected. The hypothesis was confirmed, as Latina mothers reported greater knowledge about autism over time,  $t(17)=2.91, p<.05$ . Further, Cohen's effect size value ( $d=.71$ ) suggested a moderate to large effect. Caregiver efficacy was hypothesized to increase from pre to posttest (4a). Although a trend towards increased confidence was observed, the results were moderately significant,  $t(12)=2.10, p=.05$ . The hypotheses pertaining to decreased maternal depression and caregiver burden as well as increased caregiver satisfaction were not supported.

Correlations for the Module Two pre-test variables are provided in Table 4.6, for the posttest in Table 4.7, and the pre-test/posttest in Table 4.8. One of the five hypotheses proposed for module two was supported. Hypothesis 4b indicated that efficacy in using the intervention strategies would increase from pre to posttest. Analyses revealed significant increases in efficacy from pre to post test,  $t(12)=4.43, p<.05$ . The Cohen's effect size value ( $d=1.37$ ) indicated a high practical significance. No significant differences were found for the severity of children's autism symptoms, caregiver burden, caregiver satisfaction, or use of strategies (see Table 3.9).

Table 4.1

Demographic characteristics

		Module 1 (n=18)	Module 2 (n=13)
Child			
Age		5.76(1.64)	6.15(1.95)
Gender			
	female	11.1	7.7
	male	88.9	92.3
Maternal			
Age		33.17(6.20)	33.62(6.86)
Ethnicity			
	Mexican/Mexican-American/Chicano	83.3	92.3
	Puerto Rican	5.6	7.7
	Other Latino & mixed Latino	11.2	--
Place of birth			
	Latin America	83.3	84.6
	United States	5.6	7.7
	Other Latin America	11.1	7.7
Years in the US		11.97(4.41)	12.99(4.62)
Education level			
	less than 8th grade	16.7	7.7
	8-11th grade	55.6	53.8
	HS grad/GED	11.1	7.7
	Associate's Degree	--	3.08
	Graduate Degree	16.7	--
Income			
	0-4999	11.1	7.7
	5000-9999	11.1	--
	10000-14999	33.3	30.8
	15000-19999	22.2	23.1
	20000-24999	5.6	--
	25000-29999	16.7	38.5
Employed			
	full time	5.6	23.1
	part time	11.1	--
	no	77.8	76.9
	missing	5.6	--
Married or living with partner		83.3	84.7

Table 4.2

Module 1 Correlations among Pretest Variables (N=18)

	1	2	3	4	5	6	7	8	9	10	11
1. Understand Your Child's Needs & Strengths	--										
2. Know Your Rights	.29	--									
3. Accessing the Community	.74***	.50*	--								
4. Help Your Child Develop & Learn	.71***	.63*	.67**	--							
5. Having Support Systems	.58*	.61*	.74***	.74***	--						
6. Total Family Outcome	.74***	.76***	.88***	.88***	.90***	--					
7. Knowledge about Autism	.16	-.14	.14	-.16	-.08	-.03	--				
8. Maternal Depression	-.31	-.05	-.38	-.12	-.40	-.31	-.30	--			
9. Caregiver Efficacy	.54*	.62*	.74***	.68**	.83***	.83***	-.25	-.16	--		
10. Caregiver Burden	-.12	.28	.23	.09	.08	.17	-.05	.21	.24	--	
11. Caregiver Satisfaction	.39	.07	.46	.37	.34	.38	.23	-.22	.55*	.06	--

Note: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 4.3

Module 1 Correlations among Posttest Variables (N=18)

	1	2	3	4	5	6	7	8	9	10	11
1. Understand Child's Needs & Strengths	--										
2. Know Your Rights	.28	--									
3. Accessing the Community	.18	.24	--								
4. Help Child Develop and Learn	.77***	.40	.38	--							
5. Having Support Systems	-.21	-.24	.33	-.04	--						
6. Total Family Outcome	.53*	.47	.79***	.76***	.43	--					
7. Knowledge about Autism	.19	.33	-.15	.04	.51*	-.14	--				
8. Maternal Depression	.19	.40	-.17	.31	-.41	.01	.49*	--			
9. Caregiver Efficacy	.39	.09	.45	.36	.33	.55*	.25	.01	--		
10. Caregiver Burden	.32	.15	-.13	.26	-.27	.03	.38	.34	.07	--	
11. Caregiver Satisfaction	.11	.12	.23	-.07	.05	.14	.57*	.10	.66**	0.10	--

Note: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 4.4

Module 1 Correlations comparing Pretest (vertical) and Posttest (horizontal) Variables (N=18)

	1	2	3	4	5	6	7	8	9	10	11
1. Understanding Child's Needs & Strengths	.49*	-.26	.12	.33	.06	.22	-.40	-.28	.24	-.22	-.10
2. Know Your Rights	.44	.19	.20	.30	.12	.38	-.11	.21	.25	.09	-.009
3. Accessing the Community	.52*	-.17	.42	.41	.17	.44	-.07	-.10	.60*	-.16	.15
4. Help Your Child Develop & Learn	.53*	.02	.33	.39	.26	.49*	-.24	-.10	.45	.09	.06
5. Having Support Systems	.22	-.04	.39	.19	.38	.41	-.36	-.18	.48*	-.22	-.01
6. Total Family Outcome	-.04	.37	.38	.25	.48*	.48*	-.26	-.08	.51*	-.10	.04
7. Knowledge about Autism	.03	.02	-.05	-.18	-.14	-.13	.08	-.19	.19	-.28	.14
8. Maternal Depression	-.001	.49*	.09	.01	-.45	-.01	.37	.51*	-.25	.27	.22
9. Caregiver Efficacy	.23	-.07	.23	.14	.25	.28	-.07	.008	.50*	-.10	.28
10. Caregiver Burden	.07	-.02	.13	.03	.001	.07	.26	.46	.14	.44	.10
11. Caregiver Satisfaction	-.02	-.30	.02	-.21	.44	.03	.04	-.19	.63*	-.26	.60*

Note: \* $p < .05$

Table 4.5

Module 1 Means, Standard Deviations, T-test, and Cohen's *d* for Outcome Variables

	Pre		Post		<i>t</i>	p	Cohen's <i>d</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Understanding Child's Needs & Strengths	8.50	3.05	13.94	1.66	8.68***	0.000	2.29
Know Your rights	9.00	5.83	17.28	2.35	5.99***	0.000	1.59
Accessing the Community	13.83	6.26	19.44	3.68	4.13**	0.001	1.05
Help Your Child Develop & Learn	9.06	4.09	13.39	3.12	4.51***	0.000	1.09
Having Support Systems	9.56	6.34	15.11	3.58	3.95**	0.001	1.01
Total Family Outcome	49.94	21.45	79.17	8.75	6.56***	0.000	1.94
Knowledge about Autism	18.06	2.51	20.00	1.53	2.91*	0.010	0.71
Maternal Depression	25.50	14.19	23.50	15.79	-0.57	0.580	-0.14
Caregiver Efficacy	12.33	3.97	14.06	2.48	2.10†	0.051	0.54
Caregiver Burden	13.33	7.30	16.17	5.17	1.75	0.097	0.43
Caregiver Satisfaction	12.61	2.67	12.72	2.14	0.22	0.832	0.05

Notes: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ , † $p = .05$ ; Cohen's *d* calculated using Morris and DeShon's (2002) equation 8 which corrects for dependence between means.



Table 4.6

Module 2 Correlations among Pretest Variables (N=13)

	1	2	3	4	5	6	7	8	9	10	11
1. ABC Sensory	--										
2. ABC Relating	.60*	--									
3. ABC Body Use	.70**	.54*	--								
4. ABC Language	.45	.21	.49	--							
5. ABC Social & Self Help	.17	.43	.35	.45	--						
6. Total ABC	.80***	.76**	.84***	.69**	.61*	--					
7. Caregiver Efficacy	.52*	.33	.07	.13	-.21	.25	--				
8. Caregiver Burden	.19	.12	.24	.07	.35	.25	.09	--			
9. Caregiver Satisfaction	.60*	.005	.21	.28	-.17	.26	.46	-.003	--		
10. Efficacy	.38	.41	.16	.12	.18	.34	.57*	.64*	.24	--	
11. Use of Strategies	.51*	.47	.35	.45	.45	.60*	.34	.46	.30	.75**	--

Note: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 4.7

Module 2 Correlations among Posttest Variables (N=13)

	1	2	3	4	5	6	7	8	9	10	11
1. ABC Sensory	--										
2. ABC Relating	.40	--									
3. ABC Body Use	.67*	.02	--								
4. ABC Language	.38	.78**	.00	--							
5. ABC Social & Self Help	.67*	.62*	.56	.63*	--						
6. Total ABC	.83***	.70*	.64*	.71*	.91***	--					
7. Caregiver Efficacy	-.16	-.08	-.25	-.41	-.15	-.31	--				
8. Caregiver Burden	-.06	-.02	.01	-.15	-.17	-.09	.44	--			
9. Caregiver Satisfaction	-.11	-.30	-.13	-.48	-.19	-.33	-.82**	.13	--		
10. Efficacy	.12	-.12	-.14	-.18	-.01	-.11	.60*	-.08	.81**	--	
11. Use of Strategies	.37	.40	.16	.15	.29	.35	.48	.45	.34	.50	--

Note: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 4.8

Module 2 Correlations comparing Pretest (vertical) and Posttest (horizontal) Variables (N=13)

	1	2	3	4	5	6	7	8	9	10	11
1. ABC Sensory	.53	.10	.57*	-.02	.49	.45	.19	.32	.11	.11	.12
2. ABC Relating	.29	.23	.20	-.11	.11	.19	.05	.06	-.15	.03	.18
3. ABC Body Use	.20	.001	.57*	.04	.41	.35	-.04	.21	-.18	-.24	-.09
4. ABC Language	.36	.38	.17	.72*	.62*	.58*	-.19	.07	-.26	.03	.13
5. ABC Social & Self Help	.56	.32	.46	.47	.34	.60*	-.49	-.17	-.37	-.01	.29
6. Total ABC	.54	.28	.56	.31	.57*	.61*	-.13	.15	-.24	-.03	.17
7. Caregiver Efficacy	-.06	.09	-.19	-.29	-.07	-.21	.66*	.14	.76**	.77**	.24
8. Caregiver Burden	.23	.13	.36	.05	.09	.25	.02	.61*	.09	.10	.64*
9. Caregiver Satisfaction	.44	-.05	.33	-.006	.34	.28	.27	.14	.40	.18	-.05
10. Efficacy	.09	-.13	.14	-.31	-.18	-.09	.42	.62*	.43	.43	.61*
11. Use of Strategies	.38	.33	.38	.23	.27	.44	.18	.67*	.03	.11	.73*

Note: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 4.9

Module 2 Means, Standard Deviations, T-test, and Cohen's *d* for Outcome Variables

	Pre		Post		<i>t</i>	<i>p</i>	Cohen's <i>d</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
ABC Sensory	10.08	7.26	11.46	6.84	0.73	0.482	0.22
ABC Relating	19.23	7.18	18.38	6.33	-0.36	0.724	-0.10
ABC Body Use	15.46	8.01	13.92	9.77	-0.66	0.521	-0.19
ABC Language	16.92	7.78	13.77	8.43	-1.87	0.086	-0.52
ABC Social & Self Help	16.85	6.52	13.54	5.03	-1.76	0.103	-0.50
Total ABC	78.54	26.03	71.08	26.95	-1.14	0.275	-0.32
Caregiver Efficacy	14.85	2.30	15.15	2.30	0.59	0.568	0.16
Caregiver Burden	14.38	5.06	15.46	5.99	0.78	0.449	0.22
Caregiver Satisfaction	13.31	1.65	13.38	1.56	0.16	0.877	0.04
Efficacy**	18.69	7.05	26.54	3.71	4.43	0.001	1.37
Use of Strategies	26.46	7.86	29.15	6.27	1.79	0.099	0.52

Notes: \*\* $p < .01$ ; Cohen's *d* calculated using Morris and DeShon's (2002) equation 8 that corrects for dependence between means.

## Discussion

The purpose of this study was to introduce and evaluate a culturally informed model of intervention for Latino families with children on the autism spectrum. The central research question for this study was, “*How does a culturally-informed model of autism intervention affect knowledge of ASD and services among Latino families?*” Pre and post test questionnaires designed to assess caregiver knowledge about the intervention components were compared to assess the feasibility of the intervention among Latino parents of children with ASD.

Given the different information included in the two intervention modules, separate hypotheses were developed for each of the modules. For Module 1 increases in 1a) caregiver understanding of their child’s needs and strengths, gains in knowledge of their rights, increased information about accessing their community, enhanced understanding about how to help their child develop and learn, growth in caregiver know-how about support systems, and increases in caregiver knowledge about autism symptoms were expected. The findings on the Family Outcome Survey confirmed hypothesis 1a. Latina mothers reported greater levels on each of the subscales and total scores on their posttest compared to the pretest. Specifically, they reported greater understanding of their child’s needs and strengths over time, enhanced knowledge of their rights and how to advocate for their child, obtaining more information about how to help their child develop and learn increased knowledge of support systems, and greater access to the community. The increases suggest that participation in Module 1 expanded Latina mothers’ knowledge about their child and advocacy strategies. Latina mothers reported greater understanding of their child’s needs and strengths and felt like they could better help their child develop and learn post Module 1. This finding suggests that the mothers were better equipped for their caregiving role. Gains in the three other subscales including knowing their rights, accessing

the community, and having support systems suggests mothers' ability to advocate for their children and themselves was affected over time. Their increased knowledge about how to access their community and social supports may have a supplementary impact on their psychological well-being (Bromley et al., 2004).

For Module 1 it was also hypothesized that 2a) increases in caregiver knowledge about autism symptoms would occur over time, 3a) maternal depression would reduce from the beginning of the intervention to the conclusion, 4a) caregiver confidence and satisfaction would increase, and 5a) caregiver burden would decrease over time. Hypothesis 2a was confirmed whereby increases in caregiver knowledge about autism were observed from pre- to post-test. Caregiver efficacy was marginally enhanced from pre to posttest. Although this finding was only marginally significant it is possible that a larger sample will yield more powerful results. According to Jones and Prinz (2005) increased caregiver efficacy suggests that mothers may also be able to exhibit more effective parenting. Together, the gains indicate that mothers' gained more information about ASD and how to help their child, as well as greater efficacy to care for their child after participating in Module 1 of the intervention. The hypotheses pertaining to decreased maternal depression and caregiver burden as well as increased caregiver satisfaction were not supported.

It is also important to note that large effect sizes were observed for the Family Outcome Survey subscales and knowledge about autism measure. The effect sizes suggest the intervention had high practical significance and confirm hypotheses that Module 1 would foster mothers' knowledge about autism symptoms. Furthermore, the effect sizes imply the feasibility of Module 1 with the target population.

For Module 2 increases in caregiver confidence and satisfaction, reduced caregiver burden, increases in efficacy of using the intervention strategies and greater use of the intervention strategies were expected from pre to posttest. While efficacy in using the intervention strategies increased over time, no other hypotheses were confirmed. The efficacy results suggest that after participation in Module 2, mothers felt more confident in using strategies to improve child behaviors, communication, and social interaction. The mothers' increased efficacy suggests they will be more involved in developing their child's skills and managing their child's behaviors (Hastings & Brown, 2002). No significant changes were observed for caregiver burden, caregiver satisfaction, or use of strategies. It is possible that the small sample size limited the amount of changes in these variables.

The increases in caregiver knowledge about ASD, their child's needs, advocacy strategies, and efficacy to work with their children on communication development, social interaction skills, and management of problems behaviors suggests early evidence of the utility of the culturally informed and community centered intervention. The intensive involvement of caregivers in the development of goals and the knowledge they gained from the intervention suggests the intervention enhanced the capacity among Latino families. Moreover, the primary focus on parent knowledge of ASD and efficacy outcomes advances the limited research on the impact of ASD treatment among parents (Karst & Van Hecke, 2012).

The involvement of the promotoras in the developmental and implementation of the intervention and the role of FACETS staff may suggest additional capacity building in the community and improvements in the cultural responsiveness of the service delivery systems. For example, the promotoras removed the cultural and linguistic barriers families experience in accessing care and the promotoras were able to create a bridge between services and families.

Moreover, use of a promotora model is both cost-effective and sustainable (WestRasmus et al., 2012). The matching of participants in the intervention with promotoras from similar backgrounds is compliant with ethnic matching suggestions for the improvement of research with Latinos (Castro et al., 2006). Additionally, the design of the intervention and collaboration between the university and FACETS illustrates the utility of the IACC (2011) strategic plan that highlights the need for studies to include clinical practice factors, availability, family needs, and partnerships among community-based organizations. The intervention is promising in an area of research that is underdeveloped and exploratory. Given the demonstrated utility of the intervention it should serve as a preliminary model of culturally informed intervention work with Latino families of children with autism.

### **Limitations and Future Research**

This early and exploratory study has several limitations. The small targeted sample limits the generalizability of the study to Spanish-speaking, immigrant Latina mothers. While limited in scope, the implications for this population offer a great deal of insight about practice with a group ignored by autism intervention research. The study revealed culturally-informed adaptations specific to Latinos in the context of autism intervention have the capacity to enhance caregiver knowledge of autism, develop their advocacy knowledge, and improve their efficacy to work with their children on challenging behaviors. Since there have been no other interventions designed for Latino parents of children with autism the findings cannot be compared to previous work. However, the high retention rates in Modules 1 and 2 suggest the intervention design including the promotora model, home visits, flexible schedule, and module content successfully retained Latino families in the intervention. The retention rates for both modules exceeded the average retention rates found in other parent training programs utilizing the promotora method



(Ayala et al., 2010). Moreover, this is the first study to successfully recruit and retain a sample of Latino families to participate in an autism intervention.

Although the absence of a control group and randomization further reduces the generalizability the findings indicate gains in a select area of outcomes over the period of time families were involved in the intervention. The lack of longterm follow-up data prevents comments about the longterm effects of the intervention. It is promising that other research on the use of promotoras to inform parents about health information and parenting behaviors has shown initial post-intervention improvements are sustained for at least a two-year period (Ayala et al., 2010). Finally, some of the measures in Module 2 had low internal reliability scores. The measures included the caregiver efficacy, caregiver satisfaction, and social validity scales. It is possible that the low reliability scores were a result of the small sample size in Module 2.

The limitations lead to multiple suggestions for future research aimed to develop and test culturally informed models of intervention for Latino families. Follow-up visits to determine the long-term impact of the intervention on families' use of community resources and children's outcomes should be included in future work. Understanding the impact of parents' growing knowledge of autism and services on their utilization of community resources would be valuable information to determine the impact of the intervention on reducing disparities in treatment access and utilization. Additionally, a randomized control trial will be invaluable to understand the specific effects of the intervention compared to a control or treatment as usual group. Notwithstanding these limitations, it is important to note that the data presented here demonstrate important feasibility information that suggests the intervention should be tested in a randomized control trail. The intervention protocol was successful, the promotora implementation went smoothly, families responded positively to the information, and retention was high. Finally,

continued exploration of the caregiver changes, feasibility and impact of the promotora model within the context of autism intervention has the potential to reduce autism disparities and improve outcomes for Latino families.

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## **Chapter V.**

### **Conclusion**

The prevalence rates for autism have risen dramatically over the past few decades. The increased prevalence, core impairments and associated financial costs of autism have designated it as a high priority public health concern (Newschaffer et al., 2007). Autism affects children from all sociodemographic backgrounds, yet implications for study findings focused on children from racial/ethnic minority groups are continually lagging in autism research. For instance, Latino children and families have been overlooked in autism-related studies. Their family experiences and encounters with the treatment have not been voiced in the literature. It is especially disconcerting that Latinos have been left out of the autism conversation given their status as the fastest growing group of ethnic minorities in the United States. It is critical that researchers begin to specifically target Latino children with autism and their families in research to identify factors that uniquely impact their experiences and develop intervention methods that best meet their needs. This dissertation aimed to inform the research community about Latino children with autism and their families.

The purpose of this dissertation was three-fold. First, to provide a sociocultural review of Latino children with autism and their families. In chapter II, the literature pertaining to autism spectrum disorders (ASD), Latino children and families, and disparities in the diagnosis and care of Latino children with autism were reviewed. The discussion was framed with the Socio-cultural Framework for Health Service Disparities and included multiple factors at the child, caregiver, and provider levels that contribute to disparities in the early diagnosis and treatment of Latino children with autism. In addition, a summary model with implications for Latino children with autism and their families was delineated.

The second purpose of this dissertation was to explore aspects of the summary model with each of the subsequent studies included in this dissertation. Each paper enhanced the understanding of Latino families with children on the autism spectrum. Lastly, this dissertation aimed to provide suggestions for future research and practice to improve the development and implementation of programs to reach Latino children with autism spectrum disorders and their families. In this general discussion both studies are summarized, their limitations highlighted, and proximal questions and implication for research and intervention are reviewed. To conclude, suggests for future research in psychology and social work grounded in the modified Socio-cultural Framework for Health Service Disparities suggestions are provided to enhance the inclusion of Latinos in autism studies and treatment in an effort to reduce disparities are provided.

### **Study 1: Family Burden among Latino Families with Children on the Autism Spectrum**

In study 1 Latino family experiences raising a child with autism were investigated. While caregiver burden and well-being has been reviewed heavily in the literature, there is limited work on the impact of autism on family well-being and adjustment, otherwise known as *family burden*. The specific aims included identifying differences in total family burden between Latina and White mothers, separately investigating the positive (family well-being and functioning) and negative (negative family burden) impact of having a child with autism, and disentangling sociodemographic and sociocultural factors that affect family experience. Additionally, the perceived impact of autism on total family burden, family well-being and functioning and negative family burden was distinguished from caregiver pessimistic beliefs about their child's future by assessing a measure of pessimism.

Latina mothers of children with autism reported lower levels of mother-reported pessimism and overall family burden compared to White mothers. Second, a higher percentage



of Latina mothers endorsed positively worded items (family well-being and functioning) compared to White mothers while more White mothers endorsed negatively worded items (negative family burden) than Latina mothers. For example, more White mothers endorsed the item “*Other members of the family have to do without things because of my son/daughter*” than did Latina mothers. The results were inconsistent with the majority of work on the family impact of autism demonstrating negative caregiver outcomes. Yet, the results were consistent with emerging evidence from research on Latino families of children with intellectual disabilities showing that Latina mothers report greater positive impact from their child’s disability compared to non-Latina White mothers.

Child, caregiver, and family factors were analyzed to determine their predictive value on pessimism and family burden. Increased maternal age predicted higher levels of pessimism while increased family cohesion predicted lower levels of pessimism. For overall family burden, higher number of behavior problems, increased maternal age, higher maternal education, and lower family cohesion predicted greater family burden. When the family burden scale was split up into a *family well-being and functioning* scale (positively worded items) and *negative family burden* scale (negatively worded items) the predictors varied between them. Higher maternal age and lower family cohesion predicted lower levels of family well-being and functioning. Whereas, more child behavior problems, increased maternal education, and lower levels of family cohesion predicted higher levels of negative family burden. The difference in the specific factors predicting well-being and functioning compared to negative family burden suggest the experience of raising a child with autism is multifaceted. The findings support previous research on the utility of measuring positive and negative appraisals of raising a child with a developmental disability (Trute, Hiebert-Murphy, & Levine, 2007).

Family cohesion or the *emotional bonding that family members have toward one another* (Olson, Porter, & Bell, 1982) largely contributed to every model on family burden and pessimism for Latino and White families. These findings reinforce previous work that found family cohesion to influence family burden among Latina mothers of children with intellectual disability (Magaña, Schwartz, Rubert, & Szapocznik, 2006) as well as work on the impact of family cohesion on Latino family stress (Behnke, MacDermid, Coltrane, Duffy, & Widaman, 2008).

### **Study 2: Feasibility of a Culturally Informed Intervention for Latino Children with Autism**

The purpose of study 2 was to introduce and evaluate a culturally informed model of intervention for Latino families with children on the autism spectrum. The intervention was based on the Ecological Validity Framework (Bernal, Bonilla, & Bellido, 1995) developed to provide a culturally sensitive framing of treatment outcome research. The framework required adaptations to eight core dimensions including *language, persons, metaphors, content, concepts, goals, methods, and context*. The intervention, *Addressing the Informational Needs of Latino Immigrant Parents of Children on the Autism Spectrum Intervention*, was designed specifically for Latino parents of children with autism. The intervention is a psycho-education based intervention that blends evidence-based practices for autism (i.e., Applied Behavior Analysis) with culturally informed practices to specifically meet the needs of Latino children and families affected by autism and their communities. A highlight of the intervention design was the use of promotoras (community health care workers) to assist in the development of the intervention and their full implementation of the intervention with parents. The central research question for this study was, *how does a culturally-informed model of autism intervention affect knowledge of ASD and services among Latino families?*

At the conclusion of the intervention mothers reported greater understanding of their child's needs and strengths over time, their rights, how to advocate for their child, how to help their child develop and learn, support systems, and how to access the community. The findings suggest that mothers were better equipped for their caregiver and advocate roles in their children's lives. Additionally, mothers reported greater efficacy in carrying out intervention strategies with their children post intervention. The mothers' increased efficacy suggests they will be more involved in developing their child's skills and managing their child's behaviors (Hastings & Brown, 2002). The intensive involvement of caregivers in the development of goals and the knowledge they gained from the intervention suggests the intervention enhanced the capacity among Latino families. Moreover, the primary focus on parent knowledge of ASD and efficacy outcomes advances the narrow degree of research on the impact of ASD treatment among parents (Karst & Van Hecke, 2012).

It is also important to note the high retention rate for the intervention that exceeded retention rates found in other intervention work with Latino parents. The intervention is promising in an area of underdeveloped and exploratory research. Given the demonstrated utility of the intervention it serves as a preliminary model of culturally informed intervention work with Latino families of children with autism.

### **Limitations and Proximal Research Directions**

The preceding studies revealed unique characteristics and needs of Latino families of children with autism as well as innovative practices to provide intervention for them. Although the small targeted samples revealed new information in an unexplored line of research, there are several limitations of the studies that should be considered. Study 1 and 2 include small, convenience samples. Study 1 included a Latino group that was predominately born outside of

the United States, of Mexican or Puerto Rican descent, had limited income and education attainment, and resided in an ethnic enclave. This Latino group was contrasted with a highly educated, wealthy group of White mothers. These differences limit the generalizability of the findings to similar groups and comparisons. It will be important for future research to include a larger demographic of both Latino and White mothers to tease out the demographic characteristics that may mask the cultural differences between these two groups. For instance, future research should specifically recruit Latinos with higher levels of education and larger family incomes as well as White families with lower levels of education and incomes. By including a range of Latinos, within group sociocultural research questions may be addressed. For instance, acculturative stress, immigrant status, English/Spanish language proficiency, and experience with discrimination should be investigated to determine their impact on family experiences and access to diagnosis and care among Latino children with autism. Similarly, the composition of the Latino sample in Study 2 is highly constrained. It was the intent of the researchers to recruit Latino immigrant families who spoke Spanish for the intervention. However, it will be important to widen the scope of Latino families if the intervention is to be considered for use with the umbrella term of Latinos. It will be necessary then, to target Latinos from a variety of Latin American countries, generational statuses, across the spectrum of socioeconomic status, and residing in different areas of the United States. Multi-site studies utilizing the intervention will be critical to filling this gap in the research and understanding what elements of the intervention can be applied to other Latinos and those elements that should be further modified to meet their needs.

The quantitative data presented for both Study 1 and 2 illustrated several dimensions of Latino family experiences and changes over time with intervention. In addition to utilizing

quantitative data it would also be helpful to analyze the qualitative portions of the interviews in the studies. For Study 1, investigating how Latinos conceptualize and experience autism in their families would enable researcher to determine the relationship between their conceptualization and burden. Focus group data collected at the conclusion of the intervention modules in Study 2 contains qualitative responses about the participants' reaction to the components of the intervention and their suggestions for improvements. The qualitative data from focus groups would permit the exploration of the acceptability of the intervention among the participants.

Finally, the socio-cultural framework for health service disparities was partially validated in Study 1, yet there are several proposed hypotheses that necessitate future research in psychology and social work. For example, it will be valuable to investigate the impact of previous healthcare experiences, current treatment models, provider/clinician factors, and other relevant sociodemographic factors on family burden. By understanding the complexity of factors we will have a broader vision of what to include in culturally informed interventions such as that found in Study 2. Future steps for my future research include building on the modified sociocultural framework of health service disparities through the exploration of the various factors and interactions among the health, education, and community system which develop health and mental health disparities for Latino children. The implications will enhance research on Latino children and families as well as provide implications for the development of autism awareness, health promotion, and intervention models to reduce disparities.

### **Future Directions**

This section provides suggestions for future research in psychology and social work as well as practice to enhance the development and implementation of programs to improve treatment access and utilization among Latino children with autism. The suggestions are framed with the Socio-cultural Framework for Health Service Disparities as they encompass entry points

for intervention at the macro, meso, and micro levels. Several of the suggestions are directly linked to the studies included in this dissertation while others are distal and derived from the literature review included in Chapter II.

At the macro level efforts must be made to advocate for increases in federal and state funding for research and targeted preventive and primary care interventions that focus on autism for Latino families. Several states have expanded health care coverage to include autism intervention. To improve access to health insurance as a pathway to autism intervention, funding for health and mental health care should be made a priority in budgeting for social programs. Psychologists can highlight the detrimental effects of the absence of health care coverage on children and families to serve as arguments for policy reform. Expanding access to health care services for Latino children and their families will require social workers to link eligible but not enrolled families to health care services. For non-eligible families the goal requires raising eligibility cutoffs to 250% of the poverty level for Medicaid, the State Child Health Insurance Program, and prenatal care programs for poor and working-class Latino families, especially those without employee-linked health benefits.

For immigrant families, efforts should be channeled to promote policies that extend services without citizenship requirements. In a pressing economic climate that includes a heightened anti-immigrant focus this suggestion is certain to be a challenge. However, social workers are especially equipped to garner support from a variety of non-profit, social agencies, and community-based organizations to increase the likelihood of expanding services to immigrant children and families. Additionally, policies to enhance the availability of Spanish language materials about health/mental health, with a special consideration of autism related materials must be included in efforts to enhance public awareness of the importance and need for

early diagnosis and care among Latinos. Moreover, policies should mandate adequate interpreter services in the medical and educational systems. Lastly, health, mental health, and educational systems should work in tandem to modify existing policies that prevent coverage of autism related services. Through innovative policies the route to diagnosis and treatment can be streamlined to better accommodate the needs and resources of families with children on the spectrum.

At the macro level the environmental context impacts access to diagnosis and treatment. Here suggestions to decrease disparities include a focus on addressing the underlying impact of poverty on access to care among Latino families is critical. Psychologists, in particular developmental psychologists, can aide in the knowledge development about the impact of poverty on families. Social workers may take the lead as advocates for the families by calling for and supporting legislation and policies that promote economic equity. Such policies include securing a minimum living wage, providing employment-linked health benefits, and increasing access to adult education and literacy programs (Zambrana & Logie, 2000). Social workers must engage in macro practice to highlight the need for equitable policies at the organization, community, state, and federal levels to reduce the conflux of barriers Latino children and families face in accessing health care. Furthermore, social workers should utilize macro practice to enhance coverage of autism related services under health insurance in every state.

At the meso level, the improvement of recruitment and retention methods to include Latino children and families in autism related studies is essential. As demonstrated by both study 1 and 2, strategies to improve the recruitment and retention include partnering with universities and researchers invested in minority focused research projects and familiar with community-based methods which have been shown to be successful with the recruitment of racial/ethnic

minority populations (Yancey, Ortega, & Kumanyika, 2006). A collective set of provisions such as educational, vocational, community, and family supports should be included in longitudinal research on racial/ethnic minority children with autism (Ozonoff, Goodlin-Jones, & Solomon, 2007). Provisions specific to the needs of Latino families must be considered to retain them in studies for prolonged periods of time. Including the provisions and coupling them with suggestions from studies on Latino children and families, such as that found in this dissertation, are more likely to address the varied needs of the Latinos and retain them in longitudinal and intervention studies. For example, Study 2 which tested the feasibility of a culturally-informed model of autism intervention included several key provisions was found to successfully employ a culturally-informed model of care, garner a positive participant response to the information, and retain a large proportion of families. Psychologists and social work researchers

Enhancing workforce diversity within the health care and educational systems is an important intervention to consider at the meso level. As demonstrated in this dissertation, increasing the number of Latino researchers in psychology and social work focused on autism has the potential to advance the development of theoretical models to understand disparities, pursue appropriate research questions and study designs, as well as develop culturally informed interventions. Furthermore, studies 1 and 2 illustrate the utility of bilingual and bicultural research staff to recruit and retain Latino children and families in autism research. At the practitioner level, enhancing workforce diversity requires the active recruitment of Latinos to medical, social work, psychological, teaching, and related programs. Furman et al. (2009) highlighted several strategies to advance the recruitment and retention of Latinos in various fields of practice. They suggest financial and/or academic compensation for multilingual ability and active support through mentorship to enhance retention and completion. Support should be



maintained for Latino practitioners in the field through supervision comprised of case debriefings, opportunities to develop critical consciousness, and that which promotes psychological well-being.

Enhancing workforce diversity may also positively impact community engagement with Latino families and children to reduce negative perceptions of health care and educational systems at the meso level of the community system. This can be accomplished through community based participatory research and outreach efforts which engage Latinos in the research process. Incorporating the experiences of Latino children and families into the design of services for Latinos is imperative. Improvements to the organizational culture and climate within health and educational systems may encourage Latinos to utilize available services. This could be done through strategic efforts to include Latinos in the organizational culture and structure of health and educational systems. For instance, in Study 2 Latina mothers with children on the spectrum were recruited as promotoras to participate in the design of the intervention and fully implement the intervention with families. Social workers can facilitate the inclusion of Latinos by serving as liaisons among parents, staff, and administrators within various systems. As liaisons, social workers can enhance the partnerships and communication among the different parties to enhance positive impacts on Latino children and families. The suggestions made here may reduce residential segregation and isolation, two major goals to target with interventions at the meso level that may improve access to diagnosis and care among Latino children.

Interventions at the micro level within the health care and educational systems includes addressing attitudes towards and perceptions of clients and improving provider training and resources. It is critical to develop cultural awareness to avoid contributing to oppression when working with clients from other cultures such as Latino children and families. Health care and

educational professionals should be trained to increase their cultural awareness and make use of creative and collaborative strategies to work with Latino families.

Psychologists and social workers who are entering or currently work in the health, mental health and educational systems are more likely to encounter Latinos in their work. Social workers are particularly equipped to work with Latino populations given their “person in environment” concentration, training in clinical assessment, treatment, and referral, in addition to specialized knowledge of community resources (Manoleas, 2008). Social workers have an ethical obligation to the profession to

“(a) ... understand culture and its function in human behavior and society, recognizing the strengths that exist in all cultures.

(b) ...have a knowledge base of their clients' cultures and be able to demonstrate competence in the provision of services that are sensitive to clients' cultures and to differences among people and cultural groups” (NASW, 2008).

Given their cultural preparedness social workers are trained to provide tailored services to families and have the ability to mediate the patient/provider interaction by serving as patient advocates, health educators, and cultural brokers. Similarly, the American Psychological Association (2010) ethics and code of conduct emphasizes their responsibility to be aware of cultural and sociodemographic differences and acknowledge them in the treatment process.

Within the health, mental health, and educational systems psychologists and social workers often have early contact with parents of children suspected of having a developmental delay. Therefore, psychologists and social workers must also be equipped to discuss autism treatment options with families. As demonstrated in Study 1 Latino families may experience autism in a different way than what is known about the experience from the available research.

Therefore, it is necessary for psychologists and social workers to be attentive to Latino families' specific strengths and needs as well as culturally-informed practices with Latino children with autism and their families. In order to facilitate the role of social workers in these dual roles, psychologists and social workers should be provided education and training about autism and diversity across community, treatment, and multiple service systems. This will require concentrated effort on the part of organizations such as the American Psychological Association (APA), National Association of Social Work (NASW) and Council for Social Work Education (CSWE). APA, NASW, and CSWE should strive to collaborate with universities and programs offering continuing education units (CEUs) to develop courses and trainings relevant to understanding Latino families, autism, diversity, treatment access and delivery, and Spanish terminology. These courses and trainings will address competency areas (i.e., engage diversity and difference in practice) and practice behaviors that guide social work and ethical standards of psychologists. Ideally, these CEUs should be offered at minimal to no cost to practitioners who work with Latino children and families. The additional training will foster the roles of psychologists and social workers to support Latino children with autism and their families in culturally-informed methods and with family-centered approaches.

Within the community system at the micro level, Latino parents and children should be viewed with a sociocultural lens to develop individualized programs that fit their varied needs. Using the sociocultural lens requires consideration of micro factors at the child level such as gender, race, number of ASD symptoms and severity, documentation status, and family income. Additionally, acculturation, language, beliefs, competing needs, prior experience with health/mental health and educational systems, and health literacy at the parent level must be factored into treatment options. Study 1 begins to explore the host of factors that affect Latino

families with children on the autism spectrum. The findings imply that a sociocultural framework that includes the investigation of child, caregiver, and family factors will aid in understanding Latino family experiences and increase their access and utilization of autism intervention services.

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