

## ABSTRACT

### SUPPORT GROUP FOR LATINO PARENTS OF YOUTH DIAGNOSED WITH AUTISM SPECTRUM DISORDER: A GRANT PROPOSAL PROJECT

By

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Latino parents of youth with autism spectrum disorder (ASD) experience numerous challenges when seeking services for their children including lack of support from medical providers, lack of knowledge on autism services, and cultural barriers that impede them from appropriately advocating for them. The purpose of this project was to write a grant proposal to develop a support program for low-income Latino parents of youth with ASD in Inglewood, California. The goal of the program is to increase awareness of ASD and improve access to services through various educational workshops for these parents. Subsequently, Latino parents of youth with ASD will be equipped with the skills needed to be a more effective advocate for their adolescents. The actual submission of this grant program was not required for the completion of the project.



SUPPORT GROUP FOR LATINO PARENTS OF YOUTH DIAGNOSED WITH  
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## CHAPTER 1

### INTRODUCTION

#### Problem Statement

Autism Spectrum Disorder (ASD) is a developmental disability that is defined by impairments in communication, social skills, and behavioral skills (Centers for Disease Control and Prevention [CDC], 2014a). Symptoms may vary from one individual to the next, though the most common include repetitive behaviors and difficulty expressing needs through verbal or physical gestures. Symptoms manifest at an early age and continue throughout their lives (CDC, 2014a). It remains unclear as to what causes ASD, though reports indicate that both genetics and the environment can be involved (Weintraub, 2011). The earlier a child is diagnosed the greater the impact on the child's development (CDC, 2014a). According to the CDC (2014a), the ideal age for diagnosis is 18 months to two years old; unfortunately many children do not get diagnosed until they are much older. There are numerous instruments that are used by clinicians to determine ASD.

It is estimated that 1 in every 68 children in the United States are affected by ASD (CDC, 2014a). According the CDC (2014), approximately 1 in 42 boys and 1 in every 189 girls are affected. Researchers have also found ethnic disparities in ASD diagnosis. African American and Latinos are less likely to have previous medical documentation of ASD classification when compared to Non-Hispanic Whites (Mandell et al., 2009). As a



result, disparities of diagnosis adversely impact parents and children affected by ASD. Latino families in particular can be affected by a delayed diagnosis of their children. Multiple factors may contribute to a delayed diagnosis such as lack of knowledge about services and clinicians' misdiagnosis (Mandell et al., 2009).

According to Magaña and Smith (2013) many Latino parents lack the appropriate knowledge about ASD which can impede them from obtaining the necessary services for their children. Financial hardships also make it difficult for Latino parents to get the appropriate resources for their children (Magaña & Smith, 2013). The assessment process can also be quite challenging for Latino mothers. According to Magaña and Smith, Latino mothers have a difficult time understanding the language being use during ASD assessments and experience cultural conflict that can hinder them from fully providing appropriate responses to clinicians. As a result, caring for their loved ones affected by ASD can take a toll on their psychological well being (Smith, Greenberg & Seltzer, 2012).

Caring for a child with ASD can be challenging for many parents. According to Clifford and Minnes (2013) parents of children with developmental disabilities experience more stress than typically developed children. Unfortunately, for many Latino parents the cultural barriers, lack of support, and knowledge on services can greatly impact their stress level. It was found that Latino parents experience more stress during an assessment process because they have difficulty distinguishing normal cultural behaviors from ASD behaviors (Magaña & Smith, 2013).

Such findings on Latinos and ASD create great concern on the need for support and services for Latino parents as their children reach adolescence. Caring for a child

with ASD can be overwhelming for Latino parents, but because adolescence brings additional changes in the biological and social development of youth, the need for support is much greater. For example, youth with ASD experience more anxiety than typically developed youth (White & Roberson-Nay, 2009). This can create a challenge for Latino parents, as they may lack the skills on how to adequately assist their youth during episodes of anxiety. Another challenge for Latino parents may include not understanding how to provide support for their youth in order to increase their drive to engage in social interactions (White & Roberson-Nay, 2009). In addition, Latino parents may not know how to deal with issues of victimization towards their youth, such as being bullied by peers therefore, it is important to educate and support Latino parents of adolescents with ASD to create a more positive outcome for their families (White & Roberson-Nay, 2009).

#### Purpose

The purpose of this project was to write a grant proposal to develop a program that would support Latino parents of youth ranging from 12 to 18 years of age, diagnosed with ASD. The proposed program includes educational and cognitive based support for low-income Latino families affected by ASD in Inglewood, California. The Westside Regional Center is a state program which was selected as the host agency for this program as it provides information and services for individuals and families affected by ASD, intellectual disabilities, cerebral palsy, and epilepsy. Social workers and a behavioral interventionist will collaborate to educate parents on ways to effectively support youth with ASD. Throughout the proposed program, staff will aim to help Latino parents acquire knowledge on ASD and find healthy coping strategies when caring for a

youth affected by ASD. The proposed program was developed as a 12 month resource to provide education to Latino parents about the diagnostic process, resources for youth with ASD, intervention strategies for the home, knowledge of individualized education program meetings, and healthy coping strategies for parents.

#### Multicultural Relevance

Though the program was developed to assist the Latino population it is open to parents and caregivers of any ethnic group. It is also open to individuals from all genders, sexual orientations, and cultural backgrounds. Program handouts and activities are available in both Spanish and English to accommodate the different language needs of the parents. Program staff is also required to practice cultural sensitivity by using appropriate language, body gestures, and proper clothing attire during sessions. Parents who express difficulty attending the sessions due to lack of transportation will be provided with weekly bus tokens to be used to access public transportation. The concerns and questions of every parent will also be taken into consideration when planning the topics to be discussed in the subsequent sessions. The collaboration between staff members and the type of workshops that will be provided to Latino parents of ASD youth can develop into a promising program.

#### Social Work Relevance

Providing service is one of the core values of the National Association of Social Workers Code of Ethics (NASW; 2014). Therefore, it is the responsibility of social workers to provide adequate services in a respectful manner to parents and caregivers of youth with ASD. Families affected by ASD require the support of social workers and other parents affected to fully address their needs and concerns regarding their youth.

This grant proposal is intended to create awareness about the need for programs that will support Latino parents with youth affected by ASD. This project also educates social workers about ways to provide culturally sensitive services to Latino families affected by ASD.

### Conceptual Definitions

*Autism spectrum disorder (ASD):* Autism spectrum disorder is a developmental disability defined by impairments in communication, social, and behavioral skills (CDC, 2014a).

*Latino:* Latinos are individuals that belong to a large heterogeneous group and whose origins are from any of the following, Mexico, South America, Central America, or the Caribbean (Magaña & Smith, 2013).

## CHAPTER 2

### LITERATURE REVIEW

The literature provided will focus on the challenges of ASD among Latino youth and their parents. Due to the limited literature that is available on Latino youth with ASD, literature on Latino children will be examined to further understand the challenges Latino parents face when caring for youth affected by ASD. The purpose of this literature review is to create awareness of the challenges faced by Latino parents and their adolescents, and the importance of ASD support programs. Support programs that educate and promote healthier coping skills can create more positive outcomes for Latino families affected by ASD.

#### Experiences During the ASD Diagnostic Process

The ASD diagnostic process can be stressful to parents of loved ones affected by ASD. For instance, parents and children often partake in a series of screenings and procedures to determine an ASD diagnosis. Among the most popular instruments are the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, & Couteur, 1994). These instruments allow providers to obtain data and examine particular functions of the child being evaluated (Magaña & Smith, 2013). A cross-sectional study examined the experiences of parents and caretakers in Northern Ireland of children with ASD during the ASD diagnostic process (Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). The participants of the study

were 95 parents and caretakers of children with ASD whose ages ranged from 1 to 16 years of age. The parents and caretakers were provided with various types of questionnaires in order for researchers to further understand their experiences (Keenan et al., 2010).

Keenan et al. (2010) found that 49% of parents and caretakers felt that the diagnostic process was extremely long and the information was presented in an unclear and unprofessional manner. For example, 77% of participating parents felt that the information given by providers was not sufficient because they did not receive the appropriate guidance on how to move forwards after the diagnosis (Keenan et al., 2010). Other parents expressed their dissatisfaction with professionals. For instance, one parent stated that she noticed her son was different when he was 18 months, but when she expressed her concerns a medical provider he dismissed her concerns and stated she was labeling her son (Keenan et al., 2010). It was not until her son reached 16 years of age that a teacher realized he needed to be evaluated (Keenan et al., 2010). Not being properly guided or informed about the services available to parents of children with ASD can leave parents with limited support and with unanswered questions during and after their child's diagnosis.

Similarly, the study of Sansosti, Lavik, and Sansosti (2012) examined the experiences of the ASD diagnostic process on families in Northeast Ohio. The study consisted of 16 parents and caregivers of children from ages 1 to 7 with ASD. Parents and caregivers participated in semi-structured interviews and were given various scales to measure different variables during the ASD diagnostic process. Researchers found that during the ASD diagnostic process medical providers initially dismissed many of the

concerns parents had about their children (Sansosti et al., 2012). For instance, parents stated that they raised their concerns to medical providers when their children were 24 to 36 months; however, it was only after their children were 48 months that clinicians provided their children with a diagnosis (Sansosti et al., 2012). Parents also felt that clinicians lacked ASD knowledge and as a result many became their own advocate during and after the diagnosis of their children (Sansosti et al., 2012). In addition, the study found that parents of minority children experienced longer waiting times during an ASD diagnosis (Sansosti et al., 2012). Overall, these findings demonstrate how overwhelming an ASD diagnostic process can be on families. Though, to obtain a better understanding on how different racial groups experience an ASD diagnostic process, it is important to further explore the variables that affect the outcomes on minority parents of children with ASD.

#### Delays and Misdiagnosis of ASD Among Racial and Ethnic Minority Children

According to Mandell et al. (2009) there are racial and ethnic disparities in children seeking an ASD diagnosis. The study of Mandell et al. focused on examining data from a previous cross sectional study conducted by the Autism and Developmental Disabilities Monitoring (ADDM) Network program in 2002. The study consisted of 2,568 children who were 8 years of age and resided in one out of the 14 states that were examined across the United States (Mandell et al., 2009). The participants belonged to different racial groups including American Indian, African American, Hispanic, Asian American, Native Hawaiian, White, and “other” groups.

Mandell et al. (2009) examined data from health and academic records and found that minority children from African, Hispanic, and Asian descent are less likely to have

documentation of an ASD diagnosis (Mandell et al., 2009). Researchers also found that minority children are more likely to have a lower IQ in their records as opposed to an ASD diagnosis (Mandell et al., 2009). One of the reasons for a misdiagnosis is the similarity of ASD symptoms to other disorders (Mandell et al., 2009). For example, ASD symptoms can be similar to disorders such as attention deficit hyperactivity disorder (ADHD) and obsessive compulsive disorder (OCD; Mandell et al., 2009). In addition, it was found that the educational attainment of the mothers played a role in the ASD diagnosis of minority children (Mandell et al., 2009). For example, mothers of minority children had lower educational attainments than white mothers and were less likely to have documented ASD on their child's records (Mandell et al., 2009). These findings suggest that minority children are at a greater disadvantage when seeking ASD diagnosis, which can cause for delayed services or ineffective support.

Valicenti-McDermott, Hottinger, Seijo, and Shulman (2012) examined the age of initial diagnosis of ASD in children from ethnically diverse backgrounds in Bronx, New York. The study obtained data from The Children's Evaluation and Rehabilitation Center (CERC) that serves a large population of low-income families (Valicenti-McDermott et al., 2012). The participants of the study were 399 children from ages 1 to 6 years old from African, Hispanic, Caucasian, and "other" ethnic groups. Valicenti-McDermott et al. found that from all racial groups, Hispanic and African American Children were more likely to obtain an ASD diagnosis after the age of four. By obtaining delayed diagnosis children cannot obtain the interventions needed to further their success and independence, as they grow older. Researchers also found that foreign born children and children whose mothers were not born in the United States had more difficulty obtaining earlier ASD



referrals (Valicenti-McDermott et al., 2012). In addition, delayed diagnosis was also associated to language, mannerism, and family history. For children who showed clear signs of language regression they were provided with earlier referrals (Valicenti-McDermott et al., 2012). Children displaying visible mannerisms such as toe walking were also more likely to receive earlier ASD assistance (Valicenti-McDermott et al., 2012). Lastly, the researchers found that if the child had a family member with ASD, they would obtain an immediate referral (Valicenti-McDermott et al., 2012). Although this study shows an increased support for ASD services for minority children in New York, children in this community who display mild ASD symptoms are not equally referred to ASD services. As a result, this will continue to increase the racial disparities in ASD diagnoses.

To further understand the disparities of ASD diagnosis in minority children researchers Tek and Landa (2012) conducted a study on minority toddlers with ASD. The participants of the study included 84 toddlers and their parents who were of African, Asian, Hispanic, and Caucasian descent. The study examined the language, communication, and motor skills of minority and Caucasian toddlers with ASD in the United States. Through the use of multiple questionnaires and assessments researchers found that minority toddlers from Latino, African, and Asian descent displayed more delayed language and communication than Caucasian toddlers (Tek & Landa, 2012). For example, minority toddlers displayed lower scores in understanding and expressing words. In addition, fine motor and gross motor skills were lower in minority toddlers than in Caucasian toddlers (Tek & Landa, 2012). According to Tek and Landa, such disparities can be associated to the cultural views of minority parents. For example,

minority parents may assign different cultural meanings to the subtle impairments in social and communication skills experienced by those affected with ASD (Tek & Landa, 2012). Instead minority parents may perceive more observable impairments in language and motor skills as signs of ASD (Tek & Landa, 2012). As a result, this affects how quickly parents seek an ASD evaluation for their children that can cause for a delay in ASD services. Minority parents can also disregard assistance from medical providers or ASD professionals, as they might feel that these behaviors are culturally appropriate for their toddler's age.

Additionally, Tek and Landa (2012) state that the way parents perceive the professionals and their knowledge can also affect the diagnostic process of their toddlers. For example, minority parents may perceive professionals as authority figures and may not question their practices (Tek & Landa, 2012). This may cause minority parents to feel uncomfortable in questioning or openly discussing the diagnostic process (Tek & Landa, 2012). The findings on the ASD diagnostic process and the experiences of minority children cause great concern, as studies have shown that individuals who obtain early diagnosis and interventions have better long-term outcomes (Braiden, Bothwell & Duffy, 2010). A delay in ASD diagnosis can create a challenging childhood for children, as they can experience difficulty properly addressing ASD symptoms, which can also carry on into adolescence.

### Youth and ASD

Adolescence is a period of physical, emotional, and social change for individuals. For many youth with ASD, this period of their lives can be quite challenging. White and Roberson-Nay (2009) explored some of the challenges that affect adolescents with ASD.

In their study White and Roberson-Nay examined the relationship among anxiety, loneliness, and social skills in adolescents with ASD who resided in Virginia. The study consisted of 20 participants from ages 7 to 14 years old who were verbal and had low to high IQ scores. The data was collected from both parents and youth using various questionnaires that measured behavior, social communication, social competency, responsiveness, loneliness, and anxiety levels. It was found that youth with ASD experience high levels of anxiety and have more social disabilities (White & Roberson-Nay, 2009). According to White and Roberson-Nay anxiety was linked to social loneliness when reported by the youth themselves. In addition, the findings suggest that youth with ASD experience loneliness because they lack the skills and drive to independently seek social relationship with their peers due to high levels of anxiety or depressed mood (White & Roberson-Nay, 2009). This study demonstrates how difficult it can be for adolescents to cope with social factors and the disorder.

Similarly, Vasa et al.'s (2013) study also supports previous findings on adolescents with ASD experiencing higher levels of anxiety. The cross-sectional study examined anxiety levels of children and adolescents across the country and in Canada. A total of 1,314 children and adolescents with ASD participated in the study. The participants' ages ranged from 2 to 17 years of age and were divided into groups of preschoolers (2-6 years), school age children (6-11 year), and adolescents (12-17 years; Vasa et al., 2013). Researches obtained their data through the use of semi-structured interviews, ASD behavioral intensity measures, intelligence scales, and anxiety scales. The data indicated that adolescents experience higher levels of anxiety (41%) than the school age group (26%; Vasa et al., 2013). School age children were more likely to meet

anxiety criteria (26%) than preschool children (19%; Vasa et al., 2013). The high level of clinical anxiety primarily found in youth with ASD highlights the importance of helping youth with ASD cope with anxiety. By assisting youth cope with anxiety, youth will be able to develop healthier social relationships with their peers.

Mazurek and Kanne (2010) conducted a study to further understand the impact friendship has on the symptoms of adolescents with ASD. The participants included 1,202 children who were 4 to 17 years of age and had previously participated in a North American Simons Simplex Collection program study for children with ASD. Mazurek and Kanne collected data through the use of questionnaires provided to parents and children that measured behavior, communication, intellectual functioning, motor and cognitive development. The findings of Mazurek and Kanne showed that IQ scores affect friendships of adolescents with ASD. For example, higher IQs in youth with ASD increase friendships, though it also leads youth with ASD to experience higher anxiety or depressed mood (Mazurek & Kanne, 2010). These findings are important in understanding the experiences adolescents with ASD go through when seeking social relationships. It also creates awareness about the type of support parents and caregivers of youth with ASD may need to assist their youth in experiencing smoother social relationship when transitioning from childhood to adolescence.

A study by Shattuck, Orsmond, Wagner, and Cooper (2011) explored the social participation rates among adolescents with ASD. The study analyzed data from 11,000 adolescents and parents that participated in The National Longitudinal Transitional study (NLTS) from the U.S. Department of Education (Shattuck et al., 2011). The adolescents who participated in the study were enrolled in special education, had an ASD diagnosis,

were mentally delayed, or had speech impairments. The data was obtained through interviews with parents and questionnaires provided to school staff that focused on the social participation of the adolescents with friends, general population, and social participation related to disability.

Shattuck et al. (2011) found that when compared to the other groups, adolescents with ASD were less likely to see friends outside of school or be invited to social activities. Youth with ASD were also less likely to participate in afterschool activities such as joining sports (Shattuck et al., 2011). Instead, youth with ASD were more likely to be grouped with peers of similar special needs than the other groups within the study (Shattuck et al., 2011). This study shows the numerous challenges that youth with ASD experience in social interactions as opposed to other group of adolescents in special education. Because youth with ASD are limited in social experiences and connections with peers, most of their interactions are on a one on one basis or within their home setting (Shattuck et al., 2011). This can negatively affect adolescents with ASD, as they will not be able to strengthen their social skills with other peers that can result in negative social and behavioral responses from typically developing youth.

Kloosterman, Kelley, Craig, Parker, and Javier (2013) found that the lack of social cognition and communication skills of youth with ASD plays an important role in their victimization from other adolescents. Kloosterman et al. examined bullying experienced by 24 youth with ASD, 22 with learning disabilities (LD) and ADHD, and 24 who were typically developing youth (TD). The participants of the study were 11 to 17 years of age. The data was collected using questionnaires and scales such as the ADOS-Generic (Lord, Rutter, DiLavore, & Risi, 1989), the Wechsler abbreviated scale

of intelligence (Wechsler, 1999) and the Bullying Victim Inventory Questionnaire (Olweus, 1997).

Kloosterman et al. (2013) found that youth with ASD experienced bullying, including physical, verbal, cyber, or relational bullying. While comparing youth with ASD to groups of adolescents with LD, ADHD, and TD, reports found numerous disparities. The results indicated that youth with ASD had higher rates of bullying than TD, and youth with ASD experienced more social isolation than adolescents with LD and ADHD (Kloosterman et al., 2013). Adolescents with ASD were also more likely to be physically harassed than those with an LD or ADHD diagnosis (Kloosterman et al., 2013). Although all youth with disabilities can experience bullying by their peers, those with ASD are at a greater risk due to their difficulties in social interactions (Kloosterman et al., 2013). Therefore, youth with ASD can experience more challenges during adolescent years, making it difficult for parents who lack support and knowledge on ASD to address their child's needs.

#### The Impact of ASD on Parents of Adolescents

Raising an adolescent is an overwhelming experience for parents, but for parents of youth with ASD such experience becomes more challenging. The attention and level of care that a youth with ASD requires can be quite difficult to handle with limited services or support. For instance, the phenomenological study of Strunk, Pickler, McCain, Ameringer, and Myers (2014) focused on examining the experiences of parents who care for adolescents with ASD. The study consisted of 12 parents and 10 adolescents who participated in qualitative interviews in the University of Virginia. Through the qualitative data Strunk et al. found that parents feel that they lack support

from the health care providers because they are not knowledgeable about ASD. This leads many parents to independently seek out information to try and make sense of their child's diagnosis and medications (Strunk et al., 2014). In addition, youth with ASD may suffer from an array of issues such as poor sleeping patterns, nutrition, hygiene, hormonal changes, emotional, and behavioral problems (Strunk et al., 2014). This can cause great concern for parents of adolescents with ASD; as such issues can result in aggressive behaviors from their youth.

The study of Kanne and Mazurek (2011) explored the prevalence and risk factors of children and adolescents with ASD. Researchers studied 1,380 children from ages 4 to 17 years old who had participated in a North American multi-site study based on children with ASD. The measures used in the study included the following scales: the ADI-R, ADOS, the Social Responsive (Constantino et al., 2003), Differential Ability (Elliot, 2007), and The Vineland Adaptability (Sparrow, Cicchetti, & Balla, 2005). Kanne and Mazurek found that 58% of participants exhibited a form of either mild or severe aggression towards caregivers and 32% was towards non-caretakers. This aggression in youth with ASD can be a form of escape or frustration. Not being able to perform ritualistic behaviors or finding it difficult to deal with change can trigger aggressive behaviors toward parents or themselves (Kanne & Mazurek, 2011). Experiencing such aggressive behaviors from their adolescents can be a frightening and overwhelming experience for parents. If parents do not obtain the appropriate support and knowledge about how to deescalate such behaviors they will be unable to assist their youth appropriately. Parents can also experience additional stress when caring for their adolescents with ASD that have coexisting disorders (Joshi et al., 2010).

Joshi et al. (2010) examined the challenges faced by youth with ASD who in addition had comorbid disorders. The participants consisted of 217 individuals from ages 3 to 17 years old. The participants were divided into two groups, the ASD group with 25 individuals and 192 without ASD. The data was obtained using measures such two epidemiologic versions of the Schedule for Affective Disorders and Schizophrenia for School-Age Children (Orvaschel, 1994). Through such interview measures researchers found that close to 10% of youth with ASD suffered from comorbid disorders. The comorbid disorders found in youth with ASD included agoraphobia, specific agoraphobia, encopresis, language, and compulsive disorders (Joshi et al., 2010). It was also found that parents of the adolescents who had comorbid disorders and ASD had higher levels of stress than the other parents in the study (Joshi et al., 2010). Although the findings of the study were minimal, the study represents a clear need for support and services for parents to help them effectively cope with their stress and care for their youth. In addition, parents need support to deal with the daily stressors that arise for caring for an adolescent with ASD.

Smith et al. (2010) explored the daily experiences of mothers caring for adolescents and adults with ASD. The study consisted of 96 mothers who resided in Pennsylvania and who cared for children and adults with ASD. The 8-day study used measures such as interviews questions that focused on mothers' daily stressors, positive events, and physical symptoms (Smith et al., 2010). Smith et al. found that 19% of mothers with youth and adult with ASD experienced fatigue during the 8 days than other mothers. Researchers also found that mothers of youths and adults with ASD experienced more than twice as many days of stress when compared to mothers of non-



ASD adolescents (Smith et al., 2010). In addition, mothers of ASD youth and adults spend more time caring for their loved ones than enjoying leisure time (Smith et al., 2010). The findings suggest that mothers of adolescents with ASD experience more physical and emotional challenges than other mothers. By not properly addressing these stressors, mothers can easily become overwhelmed and negatively display their stressors when caring for their adolescents with ASD.

In a similar study, McStay, Dissanayake, Scheeren, Koot, and Begeer, (2014) focused on the difference in stress among parents of children with ASD and parents of typically developing children. The participants of the study included 150 parents of Dutch children with ASD and 54 parents of typically developing children (McStay et al., 2014). The data obtained by researchers was gathered using a Parent Stress Index, Autism Severity Scale, Pediatric Inventory Scale, and a Disruptive Behavior Disorder Scale (McStay et al., 2014).

McStay et al. (2014) found that parents of children with ASD had greater levels of stress compared to parents of typically developing children. It was also found that the severity of ASD symptoms in the children affected the level of stress experienced by their parents (McStay et al., 2014). In addition, parents of children with ASD experienced increased levels of stress when their children displayed inappropriate behaviors around family and neighbors' (McStay et al., 2014). Because many parents lack knowledge on ASD, many find it difficult to explain it to family and friends (Strunk et al., 2014). As a result, such experiences can take a toll on the emotional state of parents with children affected by ASD.

Smith et al. (2012) explored the impact of social support on the well being of mothers with children affected by ASD. The study looked at 269 mothers who were part of a larger longitudinal study of 406 families of adolescents and adults with ASD in Massachusetts and Wisconsin (Smith et al., 2012). The data from this study was collected using the measures such as the Center for Epidemiological Studies-Depression Scale (Radloff, 1977), the Profile Mood States (McNair, Lorr, & Droppleman, 1971), and the Independent Behavior Revised (Bruininks, Woodcock, Weatherman, & Hill, 1996).

The data collected by researchers Smith et al. (2012) illustrated that social networks play an important role in the mood experienced by mothers of adolescents and adults with ASD. For example, mothers of adolescents and adults with ASD who experienced greater social support from friends, spouses, and other parents had higher levels of mood and wellbeing (Smith et al., 2012). The study also found that the marital status played an important role in the mood experienced by mothers of children and adults with ASD (Smith et al., 2012). Mothers who were married obtain more support from their spouses, and as a result experienced lower levels of depressed mood (Smith et al., 2012). The overall findings suggest that the need for social support is extremely valuable for the mental and physical state of parents caring for children and youth with ASD.

Khanna et al. (2011) assessed the health related quality of life among caregivers of children with ASD and those from the general population. The study examined 304 survey responses from caregivers of children with ASD who resided in Virginia (Khanna et al., 2011). The average age among the caregivers who participated in the study was 38.9 years old and participants were predominantly women. The data collected was

obtained from measures including the Short Form Health Version Caregivers Strain Questionnaire (Brannan, Heflinger, & Bickman, 1997), the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988), and the Brief Coping Orientation to Problem Experiences (Carver, 1997).

Khanna et al. (2011) found that caregivers of children with ASD have lower health scores when compared to individuals from their own age and in the general population. They also found that maladaptive coping skills and family functioning affected the quality of life of caregivers with children diagnosed with ASD (Khanna et al., 2011). Some of the maladaptive behaviors exhibited by caregivers of children with ASD included venting, denial, blame, and self-distractions (Khanna et al., 2011). The literature on parents and adolescents with ASD suggests that more support services become available for parents in order to equally address their own wellbeing and that of their youth. Though, parents of adolescents with ASD who are not culturally assimilated to the American culture can experience additional challenges when obtaining support for their families and child affected by ASD.

#### The Challenges Faced by Latino Parents of Children with ASD

Latinos parents face numerous challenges when caring for children and youth with ASD. Williams, Perrigo, Banda, Matic, and Goldfarb (2013) described the potential challenges Spanish-speaking parents can face when seeking ASD support. The simulated study conducted by the researchers took place in Los Angeles, California with over 30 agencies such as elementary schools and regional centers. The results showed that when calls were placed in Spanish, agencies and schools were quick to hang up because they could not understand what was being asked; however, English-speaking callers had a

more positive experience with an 80% in accurate responses (Williams et al., 2013). The researchers had more positive experiences setting up appointments when calling regional centers in English than Spanish-speaking parents (Williams et al., 2013). Those results demonstrate how difficult it is for Spanish speaking Latino parents to simply set up appointments for their children. This can limit Latino parents to the centers or places they can turn to, leading to a delay in services for their children.

Voelkel, LeCroy, Williams, and Holschuh (2013) conducted a study to explore the knowledge that Latinos have about ASD in the Southwest. The 169 participants of the study provided data through the use of Autism Spectrum Survey. The Autism Spectrum Survey consists of a Likert scale addressing attitudes of ASD and an acculturation scale (Voelkel et al., 2013). According to Voelkel et al. acculturation is the person's level of adapting to the mainstream culture, such as speaking the language, practicing mainstream activities, and identifying to the culture. The data obtained from the study determined that Latinos with a lower acculturation level had a more difficult time expressing themselves with confidence when communicating with professionals (Voelkel et al., 2013). For professionals this can project lack of interest or involvement from Latino parents, when in actuality Latino parents do not understand the ASD process. Voelkel et al. indicated that Latinos with lower acculturation have a difficult time obtaining and understanding ASD literature compared to Latinos with high acculturation. As a result, Latino parents can be left with minimal support and knowledge on ASD symptoms in their children or youth.

Magaña and Smith (2013) compared the differences in ASD diagnosis between Latino and Non Hispanic White adolescent and adult groups. The study consisted of 49

Latino/Hispanics and 96 Non-Hispanic Whites from Wisconsin and Massachusetts. The data was collected using the ADI-R (Lord et al., 1994). Researchers found that the Latino/Hispanic group had higher levels of impairments in gaze and imaginative social play and non Hispanic White group displayed higher levels of restrictive and repetitive behaviors (Magaña & Smith, 2013). These findings may impact the type of services offered to Latino families. For instance, the level of engagement Latinos display during social play can be open for the interpretation. For example the mothers may consider this insignificant and as a result can dismiss possible signs of ASD. Therefore, those caring for Latino children with ASD and social play impairments may not to seek assistance, as they may believe such behavior is appropriate.

In an effort to further explore the challenges that Latinos families encounter during ASD diagnosis Magaña, Lopez, Aguinaga, and Morton (2013) focused on the diagnosis and treatment services for Latino with ASD. The study consisted of 48 Latino and 56 Non Latino families whose children were 2 to 22 years of age and diagnosed with ASD (Magaña et al., 2013). The data obtained from the study was made available through the use of interviews and handouts that were provided to parents and participants. Magaña et al. found that White children were diagnosed one year earlier than Latino children. White children also had greater treatment options where they obtained more psychological, recreational, and therapeutic services than Latino children (Magaña et al., 2013). White mothers also had more flexible resources and were able to easily navigate the system for ASD services as opposed to Latino mothers (Magaña et al., 2013).

In a related study, Zuckerman et al. (2013) found that Latino children are being underserved during ASD screening. The study of Zuckerman et al. surveyed 267 primary

care pediatricians in the State of California on their ASD screenings of Latino children. Pediatricians were mailed surveys to their homes that contained questions inquiring about the history of their ASD recommendations to Latino children. The survey also asked pediatricians if they provided Spanish language screening, and if so, how confident were they on assessing Latino children (Zuckerman et al., 2013). Results showed that pediatricians had more challenges screening Latino children at risk of ASD compared to White children (Zuckerman et al., 2013). For instance, 74.5% of pediatricians reported having communication or cultural barriers during the screening process. Language barriers made it difficult for pediatricians to identify signs or symptoms of ASD among Latino Children (Zuckerman et al., 2013). Pediatricians were also less likely to conduct Spanish language screening (Zuckerman et al., 2013). The lack of support Latino parents obtain from the pediatricians adds to the challenges they have to face when seeking an ASD diagnosis for their children. As a result, many are left with more uncertainty about ASD.

Not fully understanding ASD or how to address their child's behavior can be extremely difficult for many Latino parents (Iland, Weiner, & Murawski, 2012). A recent qualitative study 96 Latina mothers in California reported the needs and obstacles they face when seeking an ASD diagnosis for their children (Iland et al., 2012). The data was collected through the use of questionnaires, a direct assessment, and The Family Needs Survey (Bailey & Simeonsson, 1988). The study found that mothers lacked information on the etiology of ASD (Iland et al., 2012). The mothers of children with ASD also lacked information on current and future services that can benefit their children (Iland et al., 2012). In addition, many mothers experienced their dissatisfaction with the

limited time they spend talking to the pediatrician about their ASD concerns (Iland et al., 2012). Overall, the mother of children with ASD expressed their desire to learn and be supported by others.

### The Reactions From the Latino Community Towards ASD

According to Zuckerman et al. (2014) seeking ASD support from their community on ASD can be difficult for Latino parents. Zuckerman et al. examined the challenges faced by Latino parents when seeking an ASD diagnosis for their children. The study consisted of 33 parents who were divided among 5 focus groups. The participants spoke English or Spanish and had children from ages 2 to 10 years old with ASD (Zuckerman et al., 2014). Data was obtained through semi-structured interviews and Zuckerman et al. found that mostly all participants expressed that they lacked knowledge on ASD. This creates great concern as Latino parents may not be knowledgeable about how to identify earlier symptoms of ASD in their children. If parents are unable to understand ASD they will have a more difficult time explaining it to family members or their community.

According to Latino parents many individuals in their community perceive disabilities or mental health problems as shameful and embarrassing (Zuckerman et al., 2014). As a result, many Latino families choose not to discuss their concerns about their children behaviors or symptoms with others. As for other members of the Latino community, the lack of knowledge about ASD can result in placing blame on the parents for the child's symptoms (Zuckerman et al., 2014). It was also reported that fathers can have an especially difficult time dealing with their child being diagnosed with ASD (Zuckerman et al., 2014). In Mexican communities many mothers reported that their

child's diagnosis was extremely difficult for fathers, as they felt it affected their manhood (Zuckerman et al., 2014). According to the mothers of this study, some fathers may see their child's diagnosis as a poor reflection on themselves as men (Zuckerman et al., 2014). This may create a sense of denial from the father and possibly place a strain on the father-child relationship. Fathers may take a more passive role in the care of their child or not fully cooperate during ASD services (Zuckerman et al., 2014). Latino fathers in the study stated that the diagnosis of their child changed the way they viewed their child's future and for many realizing that their child would not grow up to experience and follow gender roles was extremely difficult (Zuckerman et al., 2014). In addition to the family and community views about ASD, Latino parents also face financial burden when caring for their child.

#### The Financial Burden of ASD on Latino Parents

The lack of financial stability is a challenge many Latino parents face when caring for a child with ASD. For many Latino parents their lack of financial stability restricts the coverage of health insurance for their children (Zuckerman et al., 2014). As a result, this makes it difficult for parents to schedule appointments (Zuckerman et al., 2014). Attending appointments can also be difficult as many Latino parents cannot financially afford childcare services for their other children (Zuckerman et al., 2014). This may cause many Latino parents to cancel or not attend appointments at all. In addition, many parents many not have reliable transportation, which can result in late arrivals to appointments or cancellations (Zuckerman et al., 2014).

Latino parents may also work multiple jobs or not have flexible working hours, which can prevent them from taking their children to ASD services (Zuckerman et al.,



2014). In conclusion, their lack of financial means can delay the ASD process and the types of services they obtain for their children (Zuckerman et al., 2014). The experiences shared by Latino parents and their children with ASD mirrored the challenges that many parents of adolescents with ASD also experienced; therefore, it is important that the needs of Latino parents and their adolescents are not ignored. It is imperative that Latino parents obtain the adequate support in order to decrease the disparities among the services and support they obtain for their own well being and their adolescents affected by ASD.

#### The Experiences of Latina Mothers with Adolescents with ASD

To better understand the experiences of Latino parents residing with their adolescents with ASD, a qualitative study in Massachusetts was conducted by Magaña and Smith (2006). The participants consisted of 88 non-Latina White women, and 20 Latina women; a total of 108 participants. The data was examined using measures such as the Depression Scale (Radloff, 1977), the Profile of Mood States (McNair, et al., 1971), Measure of Purpose of Life, (Ryff 1989), and the ADI-R (Lord et al., 1994).

According to Magaña & Smith (2006), Latina mothers were less likely to experience fatigue or anger when compared to White mothers in the study. Researchers suggested that White mothers perhaps felt stronger emotions of anger and fatigue because their youth had more maladaptive behaviors even though Latina mothers had lower social economic status, poorer health, but overall greater psychological well being (Magaña & Smith, 2006). According to Magaña & Smith, culture may impact mothers as many Latino families foster more interdependence of family members as opposed to many Caucasian families who promote independence in their family members. In addition,

many Latina mothers find motherhood a rewarding and important role in the family which can also impact their satisfaction and overall well being when caring for their youth with ASD (Magaña & Smith, 2006). Overall this group of Latina mothers suggested that many Latino parents have culturally-based strengths when caring for their youth with ASD. Moreover, these findings suggest that family culture can help Latino parents during challenging experience. It will be beneficial for support programs to harness this strength to further improve the lives of Latino families and youth wellbeing.

#### Support Programs for Parents of Adolescents with ASD

There is a clear need for programs that can assist Latino parents of adolescents with ASD. A study in a Midwestern Autism Center examined the results of an educational program for parents of 27 adolescents with ASD, Asperger's syndrome, and pervasive developmental disorders (Schultz, Stichter, Herzog, McGhee, & Lierheimer, 2012). Pre and post measures were collected using parenting stress scales, parenting sense of competency, youth social skills, and social validity (Schultz et al., 2012). Parents who participated were taught how to assist their youth in increasing their social skills. The research found that parents of adolescents with ASD not only obtained skills to improve their youth social skills, but also obtained a sense of competency (Schultz et al., 2012). Parents reported that they felt more capable of caring for their adolescents with ASD and as a result, parents experienced lower levels of stress and were able to address their stressors more appropriately (Schultz et al., 2012). Program such as this can immensely benefit Latino families both with improving ASD symptoms of their youth, but as well improve their own health by reducing stress.

Mueller, Milian, and Lopez (2009) also examined the impact of support groups in a small qualitative study of eight Latina mothers with children from ages 4 to 16 years old and diagnosed with. The program provided support as well as education about depression, stress, and available resources for their children's individualized needs (Mueller et al., 2009). Mueller et al. found that the program-helped mothers understand the needs of their children, obtain current information, share experiences, and have a strong sense of emotional support. Such findings suggest that support programs are essential to promote a healthier quality of life for Latino families of children with developmental disabilities. Through support programs Latino parents can become more knowledgeable, confident, appropriately cope with stressors, and take more proactive roles as caretakers for their adolescent with ASD.

### Conclusion

The literature demonstrates that Latino parents caring for children with ASD undergo numerous challenges such as delayed diagnosis, misdiagnosis, cultural barriers, lack of knowledge, and lack of support from professionals. Recent literature about the support for parents and caregivers of adolescents with ASD indicates that programs combining educational and social support will help parents. Support programs will help parents develop the confidence and the skills they need to advocate for their youth and strengthen their bond as a family; therefore, it is important to make such programs more available to Latino parents in order to create the support and help them maintain an active role in the well being of their adolescents with ASD.

CHAPTER 3  
METHODOLOGY  
Target Population

The target population for this program will be Latino parents of youth with ASD who reside in Inglewood, California. Over the recent years the Latino population in the United States has increased dramatically. According to the U.S. Census Bureau (2010) the Latino population increased by 15.2 million between 2000 and 2010: this is more than half of the 27.3 million increase in the total population of the United States. Currently it is estimated that in the state of California, Los Angeles County is made up of 48.3% residents who identify as Hispanic or Latino descent (U.S. Census Bureau, 2014b).

Due to the increase of the Latino population in the United States it is important to provide support for Latino families with limited means and those who are affected by disorders such as ASD. Therefore, this program will be geared to provide support and educate low-income Latino parents of youth with ASD. The parents would be residents of Inglewood California and care for an adolescent from 12-18 years of age with ASD. Although this program is designed for Latino parents, parents from diverse ethnic backgrounds and with youth affected by ASD are welcomed to participate.

### Identification of Potential Funding Sources

Numerous methods were used in order to locate potential funding sources for the grant program. An in-depth search in state and federal funding was conducted through websites such as the U.S. Federal Government Grants ([www.grants.gov](http://www.grants.gov)) and the California State Grants ([www.ca.gov/Grants.html](http://www.ca.gov/Grants.html)). In addition, websites such as The National Institute of Health ([www.grants.nih.gov](http://www.grants.nih.gov)), The U.S. Federal Disability Programs ([www.disability.gov](http://www.disability.gov)), The U.S. Department of Health and Human Services ([www.hhs.gov](http://www.hhs.gov)), The Catalog of Federal Domestic Assistance ([www.cfda.gov](http://www.cfda.gov)), and Autism Speaks ([www.autismspeaks.org](http://www.autismspeaks.org)) were used to obtain potential funding sources.

The Internet search engine Google was also used to further explore funding for this program. The following key terms were used to locate funding: *special needs programs, funding youth, teens with disabilities, adolescents with special needs, Latinos with disabilities, caregiver programs, Latino parents support, Latino programs, parent training, ASD funding, and autism programs*. After a search of all the key terms was conducted, the results produced an array of funding sources and programs for children and adolescents with disabilities. From the results that were generated, three foundations were identified as potential funding sources: two from the National Institute of Health (NIH) and the third from the Centers for Disease Control and Prevention (CDC).

### Criteria Selection of Grant

All three foundations were thoroughly examined. The potential funders' specific interests, eligibility requirements, and the type of grants were considered when determining the funding source for the proposed program. The search for funding sources generated three potential foundations that included: The NIH's Services

Research for Autism Spectrum Disorder Across the Lifespan, The National Institute of Child Health and Human Development, and the CDC's Autism and Other Developmental Disabilities. The Services Research for Autism Spectrum Disorder Across the Lifespan foundation had specific interest in research-based programs for transitional age youth with ASD. Due to the specific requirements of this grant, it was determined that it was not suitable for the proposed program. The National Institute of Child Health and Human Development grant sought programs that focused on research and contributed to the awareness of the health of infants, children and families. This grant required particular focus on scientific practice, making it an unsuitable grant for this program. Lastly, Autism and Other Developmental Disabilities was found to be a more adequate funding source for this proposed program.

The CDC's Autism and Other Developmental Disabilities grant supported programs that can improve the developmental outcomes of children affected by ASD. The proposed program aligned well with this grant, as it focused on providing educational and cognitive support for Latino parents of youth with ASD. As a result, the program will empower Latino parents to become stronger advocates for their youth by becoming knowledgeable about adequate ASD services and support. Through this funding opportunity from the CDC the program will not only help underserved families affected by ASD but as well contribute to decreasing the disparities of Latinos youth with ASD in the United States.

#### Description of the Funding Agency

The CDC Foundation was established in 1946 by Dr. Joseph Moutin (CDC, 2014b). During the first few years the goal of the CDC was to prevent malaria all across

the nation (CDC, 2014b); however, due to the CDC's limited funding it became difficult to obtain the staff and tools necessary to wage the war on malaria (CDC, 2014b).

Today, the CDC continues to work endlessly to prevent and control infectious and chronic diseases across the nation. It continues to identify and apply disease prevention practices to promote healthy environments for people all over the United States (CDC, 2014b). Currently the CDC provides assistance and support in disease prevention and health-promoting programs that conduct research, lab investigations, maintain surveillance of diseases, and implement programs that prevent health problems and improve the lives of people all over the nation (CDC, 2014b). Additionally, the CDC foundation funds research and non-research programs that promote healthy living, play, and work environments for American all over the United States (CDC, 2014b). It is reported that the CDC awards approximately 4,200 grants and cooperative agreements that constitutes for approximately five billion dollars in federal funding (CDC, 2014b).

#### Description of Partner Agency

The partner agency for the proposed program is Westside Regional Center located in Culver City, California. The Westside Regional Center provides community resources and support to individuals with intellectual disabilities, cerebral palsy, epilepsy, and autism spectrum disorders (Westside Regional Center, 2013). These services are made available through funding from federal, state, county and other local government services, as well as private businesses. The mission of Westside Regional Center (2013) is to empower individuals with disabilities and their families to seek the necessary resources to enhance their quality of life. Each client and their families are welcomed,

integrated, and involved in every decision involving their living options, clinical care, schooling, and vocational opportunities (Westside Regional Center, 2013.)

### Needs Assessment

In order to assess the need for support programs for Latino parents' local and national studies on ASD were examined. The studies that were reviewed were gathered from California State University, Long Beach Library database and the Internet Search Engine Google. The library's social work database known as, Academic Search Complete and the database known as PsychINFO were used to gather studies on the target population. Some of the key terms used to locate studies included *ASD support*, *Latino parents programs*, *support groups ASD*, *ASD parent training*, *training on ASD*, and *autism programs caregivers*. The Internet search engine Google was also used to find statistical information on ASD youth in the state of California and the city of Inglewood, California. In addition, an ongoing communication was maintained with the staff of the Westside Regional Center to obtain information that will be useful in understanding the needs and interest of the target population. The Autism Specialist at the Westside Regional Center, Soryl Markowitz, was the main source of contact for the purpose of the grant process (personal communication, December 18, 2014). The coordinator of the family empowerment services, Ereida Galda, was also contacted to further understand the specific needs of the target population in regard to the support program.



CHAPTER 4  
GRANT PROPOSAL  
Statement of Need

According to the California Department of Developmental Services (CDDS; 2007) the rates of ASD continue to grow in California as well as nationally and internationally. From 2000 to 2007, the Regional and Developmental Centers in California had a net growth of 14,279 individuals receiving ASD services (CDDS, 2007). This dramatic growth in California centers is more than a 70% increase in caseloads (CDDS, 2007). In Los Angeles County, the Westside Regional Center makes up the highest percentage of ASD cases with more than 33% (CDDS, 2007). The Los Angeles Regional Centers serve all ethnic groups from Caucasian, Asian, African American, Hispanic and many others (CDDS, 2007). Although in the past 20 years there has been an increase of Latinos receiving ASD services, they continue to be misrepresented (Zuckerman et al., 2013).

Numerous researchers have found that Latinos affected by ASD encounter many challenges that impact their likelihood of obtaining ASD services (Mandell et al., 2009; Strunk et al., 2014; Tek & Landa, 2012). For example, these challenges can include delayed referrals from medical providers, misdiagnosis from clinicians, lack of parental knowledge, and cultural barriers that can make it difficult for Latino families to obtain the necessary ASD support to appropriately care for their youth (Mandell et al., 2009;

Strunk et al., 2014; Tek & Landa, 2012). This can cause for youth with ASD to experience more impairments as they transition into adulthood; therefore, support program that assist Latino parents of youth with ASD are extremely beneficial. Latino parents will be able to acquire the necessary tools to become empowered caregivers and provide their adolescents with a promising future.

### Program Narrative

In order to provide support for Latino parents of adolescents with ASD, the support program will serve 60 Latino parents within Inglewood, California. The program will be promoted by informing social workers in the community in an effort to obtain potential referrals. In addition, flyers will be distributed to medical providers at low-income clinics and to public schools in the community to increase referrals of potential participants.

Potential participants for the support program will be called to further assess their need for ASD support. In order to be eligible for the program Latino parents need to care for a youth with ASD, reside in Inglewood, California and have limited to no ASD resources. The participants will join one of the four support groups that will be provided within the 12-month period. Within each group 15 Latino parents will participate in two-hour sessions that will be held twice a week. The sessions will be held every other week for the duration of three months, for a total of 12 sessions per group. In order to accommodate the personal schedules of the participants in each group, morning and evening sessions will be offered. A detailed description of the sessions is provided in Appendix A.

Skilled professionals will conduct the program such as one full-time bilingual Licensed Clinical Social Worker, one part-time bilingual Master's level social worker, one part-time bilingual behavioral interventionist, and one part-time bilingual social work intern. All of the participants in the support program will receive educational and cognitive support by the staff that will include an array of topics that will be provided both in Spanish and English. The educational component of the program will consist on information on the etiology of ASD, the diagnostic process, and intervention strategies for parents, and knowledge on individualized education programs. In addition, parents will receive cognitive base support from the staff and from the members of the group in an effort to promote healthier coping skills.

#### Goals and Objectives of the Program

The following program objectives have been established to ensure the effectiveness of the program:

##### Goal 1:

Increase the knowledge of ASD among Latino parents of youth affected by ASD.

##### Objectives:

Objective 1: Provide Latino parents with information on the etiology of ASD.

Objective 2: Educate Latino parents on ASD symptoms.

Objective 3: Provide parents with intervention strategies to modify symptoms and undesirable behaviors of youth in the home and outdoor settings.

##### Goal 2:

Increase Latino parents' awareness on how to access ASD resources for youth.

Objectives:

Objective 1: Educate Latino parents on how to effectively communicate with medical providers, school staff, and ASD specialists to seek support.

Objective 2: Provide information on the regional center services.

Goal 3:

Provide Latino parents with psychosocial support as they care for youth with ASD.

Objectives:

Objective 1: Create interactive sessions with Latino parents that promote healthy coping strategies.

Objective 2: Create a comfortable and safe environment for Latino parents to verbally express their concerns and feelings about their youth affected by ASD.

Objective 3: Provide ample time for Latino parents to consult with staff and group members about concerns or questions regarding their youth care.

Evaluation of Program

To evaluate the effectiveness of the program numerous methods will be utilized. Evaluation measures will be developed to assess the effectiveness of the program. Upon entering the room and before each session parents will be provided with a sign in sheet that will monitor their participation rate. The parents will also be presented with a pre-test that will include a combination of multiple choice questions and open-ended questions on ASD. A post-test with the same questions will be provided at the end of each session, in addition to a comments section. The tests will include three multiple-choice questions and two open ended questions that will correlate with the topic for that

particular session. The comments portion of the posttest will allow participants to provide their feedback on the activities and information that was provided. Through the evaluation process staff will be available to also verbally explain the forms to parents in need of further assistance. These tests will assist staff in determining the knowledge that was gained throughout the sessions and provide the staff with feedback on areas of improvement.

### Budget Narrative

An estimated total budget of \$157,941 will be required for the implementation of the program. The budget will be allocated to the numerous expenses for the duration of the 12-month period. The budget will include staff salary, benefits, and program expenses. A detailed program line budget can be found in Appendix B.

### Salaries and Benefits

Licensed Clinical Social Worker (LCSW): The LCSW will have a full-time position for the duration of this program. The LCSW will oversee the support program to ensure the participants receive the appropriate support and resources. The position will include direct involvement during sessions as well collaborative responsibility in the development and delivery of the program sessions. In addition, the LCSW will collaborate with staff to conduct outreach events with community centers and public schools to obtain referrals of potential participants. The qualifications for this position include: A Master's degree from an accredited school in social work, must be licensed as a Licensed Clinical Social Worker in the state of California for a minimum of two years, bilingual (Spanish/English), a minimum of two year experience working with youth affected by ASD, experience in program development, and interpersonal verbal and

listening skills to communicate effectively with participants and staff. The salary for this full time LCSW will be \$ 54,000.

Master Level Social Worker (MSW): The MSW will be a part-time position. The MSW will provide support by co-facilitating the support program with the staff. The MSW will also assist the LCSW in planning the program and delivering the cognitive portion of each session. The following qualifications are required: A Master's degree from an accredited school in social work, bilingual in Spanish, a minimum of two years experience working with families affected by ASD, knowledgeable about ASD, and the ability to communicate clinically and therapeutically with participants. The salary for this part-time position will be \$ 23,000.

Behavioral Interventionist (BI): The BI will have a part-time position and will deliver the education component of the program. The BI will provide behavioral support by helping participants increase their knowledge on ASD and by coaching them on behavioral modifications in home and school settings. In addition, the BI will provide information on ASD resources such as regional center services, and other affordable services within their communities. The qualifications for this position include: A Bachelor's degree in psychology, sociology or related field from an accredited university, a minimum of three years advanced experience in Applied Behavior Analysis treatments, experience working with family, children and youth affected by ASD, knowledge in Individualized Education Program, experience conducting ASD educational meetings, knowledgeable of community resources, and strong skills in communication and working collaboratively with other staff. The salary for the BI part-time position will be \$ 13,500.

Social Work MSW Intern (SWI): The SWI will have part time position and will assist the staff during the sessions. One SWI will be recruited from local universities with accredited MSW programs to assist with the program's implementation and to learn about social work practice. The SWI will join the staff in the community outreach process by reaching out to local community center and school within Inglewood, CA. The SWI will also provide support during group sessions by assisting in the delivery of the cognitive and educational components of the program. In addition, the SWI will be responsible for the evaluation portion of the program by developing and implementing a pre and posttest to determine the validity of the program. The MSW intern will receive no compensation.

#### Government Fringe Benefits

The fringe benefits for staff that includes the LCSW, MSW, and BI will be in the amount of \$5,611. The FICA tax rate will be a 6.2% of the fringe benefits (Internal Revenue Service, 2014). The unemployment insurance amounts to \$3,077 (3.4%; Employment Development Department [EDD], 2014b) and the state disability insurance \$905 (1%) of the fringe benefits (EDD, 2014a). Workers compensation will take up 8% of fringe benefits at a total of \$7,240. The overall total for personnel salary and benefits is estimated at \$107,333.

#### Direct Program Costs

Program supplies: The program supplies include flyers, letterhead, printed pre and posttests, banners, program attire, program logo, outreach expenses, printing, and paper expenses at an estimated total cost of \$2,500.

Office supplies: The office supplies for the staff will include rims of paper, post its, pens, pencils, white out, folders, had cover binders, planners, note pads, staplers, highlighters, portable timers, batteries, and ink cartridges. Estimated total cost: \$2,000.

Equipment: The equipment needed for this program include a projector, three laptops, two office telephones, one printer, water dispenser, and a coffee maker. Estimated total cost: \$5,000.

Snacks and refreshments: Light snacks and refreshments will be provided in each session. The morning sessions will be provided with variety of breakfast pastries, coffee and juices. The evening sessions will be provided with sandwiches, pizza, snacks, juices and water. Estimated total cost: \$5,000.

Transportation: The transportation portion of the program will include bus tokens for parents who have limited means of transportation. Each participant in need will be provided with bus tokens to ensure their arrival to all sessions. Estimated total cost: \$1,750.

#### Indirect Program Costs

Administration overhead: Ten percent or \$14,358.00 of the total budget will be allocated for administrative overhead to manage the grant.

#### In-Kind Contributions

Rent and utility costs: The host agency will provide the space needed to implement this support program for a 12-month period. Estimated value: \$20,000.



## CHAPTER 5

### LESSONS LEARNED

#### Program Design

The goal of this program is to increase awareness and support for low-income Latino families affected by ASD in the city of Inglewood, California. The review of literature on Latino parents of children with ASD provided a comprehensive understanding on the need for more support programs for the target population. The challenges that Latino parents experience during an ASD diagnosis and while seeking services played a crucial role in the program design. Some of these challenges include lack of knowledge on ASD and language and cultural barriers that greatly impact the level of support Latinos parents obtain for their children (Iland et al., 2012; Zuckerman et al., 2013).

The proposed program will be beneficial for Latino parents who reside in Inglewood, CA because it will teach parents how to become effective advocates and receive additional support from other parents and staff members. Support groups have been found to not only improve the quality of life of children with ASD, but also help parents cope with daily stressors and gain stronger emotional support (Mueller et al, 2009; Schultz et al., 2012). In an effort to promote such positive outcomes for low-income Latino families affected by ASD, skilled staff and appropriate educational and

cognitive workshops will be provided in the support group for Latino parents of youth with ASD.

#### Partner Agency Selection

The Westside Regional Center was chosen as the partner agency for this proposed program. It was selected based on the population it serves and the mission of the agency. In 2012, the Regional Center served approximately 35.47% of individuals and families affected by ASD (Westside Regional Center, 2013). The agency also provides services for residents in Inglewood, CA where 50.6% of the population is Latino and 22.4% the entire population lives below the poverty level (U.S Census Bureau, 2014a). The Westside Regional Center is the ideal partner agency not only because of the target population, but also because it shares similar goals for families with ASD. The agency seeks to empower individuals and families affected with a disability through various services and participation of the clients' family unit (Westside Regional Center, 2013). Currently, the agency does not have a support group for Latino families affected with ASD, which makes the program a valuable form of support for Latino parents.

#### Identifying Potential Funding Sources

An extensive Internet search was done to identify funding sources for the proposed program. During the identification process there were many obstacles that were encountered that made it difficult to identify appropriate funding sources for the proposed program. The use of various grant databases generated an abundant list of foundations with different funding requirements, restrictions, and objectives. After extensive examination it was found that the majority of funding sources was intended for ASD

research. And although there was funding for ASD programs, many sought out non-profit organizations as opposed to private organizations.

Since the chosen partner agency is a private for profit organization it was difficult to identify a funding source that would be an appropriate fit for the proposed program. As a result, the decision was made to change from a profit to a non-profit agency to successfully identify a funding source. More funding opportunities became available after the change was made to a non-profit agency. And after careful consideration on the objectives and the requirements of these funding opportunities, the CDC was found to be a suitable foundation for this proposed program.

The CDC was the ideal funding source for the proposed program because it supports non-profit organizations that plan, coordinate or implement program that assist individuals affected by ASD or other developmental disorders (CDC, 2014b). Therefore, the proposed program aligns well with the CDC objectives. The program would in fact implement strategies to reduce racial disparities amongst individuals affected by ASD. It would provide Latino parents of youth with ASD with the appropriate tools they need to become effective advocates for their children and in the process diminish the misrepresentation of Latinos with ASD.

Through the process of identifying a funding source it became evident that there is limited funding to support programs for Latino parents of youth affected by ASD. Not having the available funds to implement a program can contribute to the lack of ASD support Latino youth receive throughout their lives. Therefore, it is imperative that funders become aware of the need for ASD program that will empower the Latino

community. It is only when the community at large becomes aware of the need for ASD support that Latinos will no longer be misrepresented in the ASD population.

### Budgeting

Developing a budget for the proposed program required an abundant amount of research. To ensure that sufficient funds were obtained research was conducted on the salaries of personnel, salary benefits, direct program costs, and indirect costs. The process was initially overwhelming due to the lack of experience in budget development. Though, after thorough research and review of budgeting components, the process became more plausible to develop. Additionally, the development of the budget served as a great learning experience. It created awareness on how the funding should be distributed in the program to effectively implement the proposed program.

### Grant Writing

The grant writing process was a challenging yet rewarding experience. It required an extensive amount of time and commitment. There were challenges throughout this process that required additional attention in order to effectively develop the program. Identifying sufficient literature that could support the target population of the program was found to be a challenge. After using distinct search methods, the appropriate amount of literature was identified and used in this process. Another major challenge was searching for funding sources that would support private agencies. After continuous research, there was a need to change to a non-profit agency, which made it easier to acquire the appropriate funding.

Although the challenges that were experienced during the grant writing process were overwhelming, it provided a great learning experience. It showed how unexpected

events could occur, and one needs to find ways to effectively change them into positive outcomes. Overall this grant writing experience provided the necessary skills and knowledge that in the near future can be beneficial for the development of large-scale programs.

### Implications for Social Work Practice and Policy

It is essential for social workers to become knowledgeable about ASD and how it affects Latinos from low-income communities. Being aware about the challenges and the benefits of services such as support groups will help social workers provide appropriate advocacy. As stated in the NASW Code of Ethics (2014) social workers need to partake in culturally competent practices to fully understand the challenges that results in social diversity and oppression. Therefore, this proposed program will serve as a way to educate social workers and other professionals on ASD and the challenges that Latinos with ASD experience.

As stated by Zuckerman et al. (2014) Latinos affected by ASD lack the support from professionals and their community. As a result, this can cause a delay in treatments for Latino youth with ASD. Therefore, social workers that are knowledgeable about ASD can serve as a great source of support for Latino parents and their adolescents. As stated by McStay et al. (2014), supporting parents and helping them build confidence in their parenting skills will not only decrease their stress level, but also promote a more active role in the decision making process involving their children treatments and overall future. In addition, social workers can also begin the discussion among other professionals and community members of the importance of developing policies that will benefit more Latinos families affected by ASD. Through discussion and further

involvement in this issue, more Latino families will be able to provide their youth with a more successful adolescence and independent adult life. In conclusion, support groups can create a more empowered Latino community. Education and cognitive supports within ASD support groups will not only teach behavioral interventions for Latino youth, but also provides competency and self esteem for parents of children with ASD (Schultz, Schmidt, and Stichter, 2011).

## APPENDICES

APPENDIX A  
WORKSHOP TIMELINE



WOKSHOP TIMELINE

Session 1	Session 2	Session 3
Wednesday	Friday	Wednesday
<u>10:00 AM - 12:00 PM</u> Defining ASD  Community's Perception on ASD	<u>10:00 AM - 12:00 PM</u> Recognizing ASD  Symptoms Parenting Coping Skills	<u>10:00 AM - 12:00 PM</u> ASD Diagnostic Process  Challenges During Diagnostic Process
<u>6:00 PM - 8:00 PM</u> Defining ASD  Community's Perception on ASD	<u>6:00 PM - 8:00 PM</u> Recognizing ASD  Symptoms Parenting Coping Skills	<u>6:00 PM - 8:00 PM</u> ASD Diagnostic Process  Challenges During Diagnostic Process

Session 4	Session 5	Session 6
Friday	Wednesday	Friday
<u>10:00 AM - 12:00 PM</u> Seeking ASD Services  Advocating for Youth	<u>10:00 AM - 12:00 PM</u> Regional Center Services Experiences with ASD Professionals	<u>10:00 AM - 12:00 PM</u> Understanding ADA Open Discussion with Parents
<u>6:00 PM - 8:00 PM</u> Seeking ASD Services  Advocating for Youth	<u>6:00 PM - 8:00 PM</u> Regional Center Services Experiences with ASD Professionals	<u>6:00 PM - 8:00 PM</u> Understanding ADA Open Discussion with Parents

Session 7	Session 8	Session 9
Wednesday	Friday	Wednesday
<u>10:00 AM - 12:00 PM</u> What is an IEP? How to Advocate for an IEP	<u>10:00 AM - 12:00 PM</u> Parents Rights in School Settings Relationship with School Staff	<u>10:00 AM - 12:00 PM</u> Youth & Peer Relationships Assisting Youth with Social Interactions
<u>6:00 PM - 8:00 PM</u> What is an IEP? How to Advocate for an IEP	<u>6:00 PM - 8:00 PM</u> Parents Rights in School Settings Relationship with School Staff	<u>6:00 PM - 8:00 PM</u> Youth & Peer Relationships Assisting Youth with Social Interactions

Session 10	Session 11	Session 12
Friday	Wednesday	Friday
<u>10:00 AM - 12:00 PM</u> Physical & Psychological Changes in Youth Coping with Youth Changes	<u>10:00 AM - 12:00 PM</u> Educating Family About ASD Family Involvement with Youth	<u>10:00 AM - 12:00 PM</u> Transitional Resources Coping with Transition
<u>6:00 PM - 8:00 PM</u> Physical & Psychological Changes in Youth Coping with Youth Changes	<u>6:00 PM - 8:00 PM</u> Educating Family About ASD Family Involvement with Youth	<u>6:00 PM - 8:00 PM</u> Transitional Resources Coping with Transition

APPENDIX B  
PROPOSED PROGRAM LINE ITEM COSTS

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Expenses for 1 Year of Proposed Program

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Personnel Salary	
100% FTE - Bilingual Licensed Social Worker	\$54,000.00
50% PTE - Bilingual Master's Level Social Worker	\$23,000.00
50% PTE - Bilingual Behavioral Interventionist	\$13,500.00
50% PTE - Bilingual Social Work Intern	\$0.00
Standard Government Fringe Benefits	
FICA Tax Rate (6.2%)	\$5,611.00
Unemployment Insurance (3.4%)	\$3,077.00
State Disability Insurance (1%)	\$905.00
Workers Compensation (8%)	\$7,240.00
<b>TOTAL PERSONNEL SALARY AND BENEFITS</b>	<b>\$107,333.00</b>
Direct Program Costs	
Program Supplies	\$2,500.00
Office Supplies	\$2,000.00
Equipment	\$5,000.00
Snacks & Refreshments	\$5,000.00
Transportation	\$1,750.00
<b>TOTAL DIRECT PROGRAM COST</b>	<b>\$16,250.00</b>
In-Kind Contributions	
Rent & Utility Costs	\$20,000.00
<b>TOTAL PERSONNEL SALARY AND BENEFITS</b>	<b>\$107,333.00</b>
<b>TOTAL DIRECT PROGRAM COST</b>	<b>\$16,250.00</b>
<b>IN-KIND CONTRIBUTIONS</b>	<b>\$20,000.00</b>
<b>ADMINISTRATIVE OVERHEAD</b>	<b>\$14,358.00</b>
<b>TOTAL PROGRAM COST</b>	<b>\$157,941.00</b>
<b>TOTAL AMOUNT REQUESTED</b>	<b>\$137,941.00</b>

## REFERENCES

## REFERENCES

- Bailey, D.B. Jr., & Simeonsson, R.J. (1988). Assessing the needs of families with handicapped infants. *The Journal of Special Education, 22*(1), 117-127.
- Braiden, H., Bothwell, J., & Duffy, J. (2010). Parents' experience of the diagnostic process for autistic spectrum disorders. *Child Care in Practice, 16*(4), 377-389.
- Brannan, A. , Heflinger, C. , & Bickman, L. (1997). The caregiver strain questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. *Journal of Emotional and Behavioral Disorders, 5*(4), 212-222.
- Bruininks, R. H., Woodcock, R. W., Weatherman, R. F., & Hill, B. K. (1996). *SIB-R: Scales of independent behavior-Revised*. Itasca, IL: Riverside Publishing.
- California Department of Developmental Services. (2007). *Autism spectrum disorders*. Retrieved from [http://www.dds.ca.gov/Autism/docs/AutismReport\\_2007.pdf](http://www.dds.ca.gov/Autism/docs/AutismReport_2007.pdf)
- Carver, C. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International Journal of Behavioral Medicine, 4*(1), 92-100.
- Centers for Disease Control and Prevention. (2014a). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report, 63*(2). Retrieved from <http://www.cdc.gov/mmwr/pdf/ss/ss6302.pdf>
- Centers for Disease Control and Prevention. (2014b). *The CDC organization*. Retrieved from <http://www.cdc.gov/about/organization/cio.htm>
- Clifford, T., & Minnes, P. (2013). Logging on: Evaluating an online support group for parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(7), 1662-1675.
- Constantino, J. , Davis, S. , Todd, R. , Schindler, M. , Gross, M. , Brophy, S, ... Reich, W. (2003). Validation of a brief quantitative measure of autistic traits: Comparison of the social responsiveness scale with the autism diagnostic interview-revised. *Journal of Autism and Developmental Disorders, 33*(4), 427-433.

- Elliot, C. (2007). *Differential abilities scale (DAS-II) Manual* (2nd ed.). San Antonio, TX: Harcourt Assessment.
- Employment Development Department. (2014a). *State disability insurance (SDI) tax*. Retrieved from [http://www.edd.ca.gov/payroll\\_taxes/State\\_Disability\\_Insurance\\_Tax.htm](http://www.edd.ca.gov/payroll_taxes/State_Disability_Insurance_Tax.htm)
- Employment Development Department. (2014b). *Unemployment insurance (UI) tax*. Retrieved from [http://www.edd.ca.gov/payroll\\_taxes/unemployment\\_insurance\\_tax.htm](http://www.edd.ca.gov/payroll_taxes/unemployment_insurance_tax.htm)
- Iland, E. D., Weiner, I., & Murawski, W. W. (2012). Obstacles faced by Latina mothers of children with autism. *Californian Journal of Health Promotion, 10*(2), 1-12.
- Internal Revenue Service. (2014). *Tax topics*. Retrieved from [http://www.irs.gov/tax\\_topics/tc751.html](http://www.irs.gov/tax_topics/tc751.html)
- Joshi, G., Petty, C., Wozniak, J., Henin, A., Fried, R., Galdo, M., & ... Biederman, J. (2010). The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. *Journal of Autism and Developmental Disorders, 40*(11), 1361-1370.
- Kanne, S., & Mazurek, M. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders, 41*(7), 926-937.
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 390-397.
- Khanna, R., Madhavan, S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 41*(9), 1214-1277.
- Kloosterman, P.H., Kelley, E.A., Craig, W.M., Parker, J.A., & Javier, C. (2013). Types and experiences of bullying in adolescents with an autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*(7), 824-832.
- Lord, C., DiLavorne, P. C., & Risi, S. (2002). *Autism diagnostic observation schedule*. Los Angeles, CA: Western Psychological Services.

- Lord, C., Rutter, M., & Couteur, A. (1994). Autism diagnostic interview-revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 24*, 659–685.
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (1989). *Autism diagnostic observation schedule*. Los Angeles, CA: Western Psychological Services.
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (1999). *Autism diagnostic observation schedule-WPS (ADOS-WPS)*. Los Angeles, CA: Western Psychological Services.
- Magaña, S., Lopez, K., Aguinaga, A., Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities, 51*(3), 141-153.
- Magaña, S., & Smith, M. (2006). Psychological distress and well-being of Latina and non-Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes towards coresidence status. *American Journal of Orthopsychiatry, 76*(3), 346-357.
- Magaña, S., & Smith, L. (2013). The Use of the autism diagnostic interview-revised with a Latino population of adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 43*(5), 1098-1105.
- Mandell, D. S., Wiggins, L. D., Yeargin-Allsopp, M., Carpenter, L., Daniels, J., Thomas, K. C., Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*(3), 493-498.
- Mazurek, M., & Kanne, S. (2010). Friendship and internalizing symptoms among children and adolescents with ASD. *Journal of Autism and Developmental Disorders, 40*(12), 1512-1520.
- McNair, D. M., Lorr, M., & Droppleman, L. F. (1971). *Profile of mood states*. San Diego, CA: Educational and Industrial Testing Service.
- McStay, R., Dissanayake, C., Scheeren, A., Koot, H., & Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behavior of children and adolescents with autism. *Autism: The International Journal of Research & Practice, 18*(5), 502-510.
- Mueller, T., Milian, M., & Lopez, M. (2009). Latina mothers' views of a parent-to-parent support group in the special education system. *Research and Practice for Persons with Severe Disabilities, 34*(3-4), 113-122.



- National Association of Social Workers (NASW). (2014). *Code of ethics of the National Association of Social Workers*. Retrieved from <http://www.naswma.org/?95>
- Olweus, D. (1997). Bully/victim problems in school: Facts and intervention. *European Journal of Psychology of Education, 12*(4), 495-510.
- Orvaschel, H. (1994). *Schedule for affective disorder and schizophrenia for school-age children epidemiologic version*. Ft. Lauderdale, FL: Nova Southeastern University, Center for Psychological Studies.
- Radloff, L. S. (1977). The CES-D scale a self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385-401.
- Ryff, C. (1989). In the eye of the beholder: Views of psychological well-being among middle-aged and older adults. *Psychology and Aging, 4*(2), 195-210.
- Sansosti, F., Lavik, K., & Sansosti, J. (2012). Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities, 27*(2), 81-92.
- Schultz, T., Schmidt, C., & Stichter, J. (2011). A review of parent education programs for parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 26*(2), 96-104.
- Schultz, T. R., Stichter, J. P., Herzog, M. J., McGhee, S. D., & Lierheimer, K. (2012). Social competence intervention for parents (SCI-P): Comparing outcomes for a parent education program targeting adolescents with ASD. *Autism Research and Treatment, 1-10*.
- Shattuck, P., Orsmond, G., Wagner, M., & Cooper, B. (2011). Participation in social activities among adolescents with an autism spectrum disorder. *PloS One, 6*(11), e27176.
- Smith, L. E., Greenberg, J. S., & Seltzer, M. (2012). Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(9), 1818-1826.
- Smith, L. E., Hong, J., Seltzer, M., Greenberg, J.S., Almeida, D.M., & Bishop, S.L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(2), 167-178.
- Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland adaptive behavior scales (2nd ed.)*. Circle Pines, MN: American Guidance Service.

- Strunk, J.A., Pickler, R., McCain, N.L., Ameringer, S., & Myers, B.J. (2014). Managing the health care needs of adolescents with autism spectrum disorder: The parents' experience. *Families, Systems, & Health, 32*(3), 328.
- Tek, S., & Landa, R. (2012). Differences in autism symptoms between minority and non-minority toddlers. *Journal of Autism and Developmental Disorders, 42*(9), 1967-1973.
- U.S. Census Bureau. (2010). *The Hispanic Population: 2010*. Retrieved from <http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf>.
- U.S. Census Bureau. (2014a). *Inglewood city, California state and county quick facts*. Retrieved from <http://quickfacts.census.gov/qfd/states/06/0636546.html>
- U.S. Census Bureau. (2014b). *Los Angeles County, California State and county quick facts*. Retrieved from <http://quickfacts.census.gov/qfd/states/06/06037.html>.
- Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Shulman, L. (2012). Age at diagnosis of autism spectrum disorders. *The Journal of Pediatrics, 161*(3), 554-556.
- Vasa, R. A., Kalb, L., Mazurek, M., Kanne, S., Freedman, B., Keefer, A., ... Murray, D. (2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*(11), 1358-1369.
- Voelkel, H., LeCroy, C. W., Williams, L., & Holschuh, J. (2013). The full spectrum: Hispanic understanding of autism. *Best Practices in Mental Health: An International Journal, 9*(1), 31-46.
- Wechsler, D. (1999). *Wechsler abbreviated scale of intelligence*. San Antonio, TX: The Psychological Corporation.
- Weintraub, K. (2011). Autism counts. *Nature, 479*(7371), 22-24.
- Westside Regional Center. (2013). *A handbook for individuals with developmental disabilities and their families*. Retrieved from <http://www.westsiderc.org/resources/educational-info/>
- White, S. W., & Roberson-Nay, R. (2009). Anxiety, social deficits, and loneliness in youth with autism spectrum disorders. *Journal of Autism & Developmental Disorders, 39*(7), 1006-1013.
- Williams, M., Perrigo, J., Banda, T., Matic, T., & Goldfarb, F. (2013). Barriers to accessing services for young children. *Journal of Early Intervention, 53*(1), 61-74.

- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52(1), 30–41.
- Zuckerman, K., Mattox, K., Donelan, K., Batbayar, O., Baghaee, A., & Bethell, K. (2013). Pediatrician identification of Latino children at risk for autism spectrum disorder. *Pediatrics*, 132(3), 445-453.
- Zuckerman, K., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicolaidis, C. (2014). Latino parents' perspectives on barriers to autism diagnosis. *Academic Pediatrics*, 14(3), 301-308.