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Pepperdine University
Graduate School of Education and Psychology

TRAINING MANUAL FOR CLINICIANS: THE CONVERSTATIONS WITH
LATINO PARENTS AFTER AN ASD DIAGNOSIS

A clinical dissertation submitted in partial satisfaction
of the requirements for the degree of
Doctor of Psychology

by

Nancy E. Guardado

May, 2018

Carrie Castañeda-Sound, Ph.D.- Dissertation Chairperson

This clinical dissertation, written by

Nancy E. Guardado

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

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DEDICATION

This is dedicated to *mi familia* Guardado. Thank you for supporting me through so many years of schooling and missing so many family gatherings because of it. This achievement is our achievement. I also dedicate this to my husband, you always find the right words to lift me up...*eres mi vida*.

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I could not have completed this dissertation without the support of my chair, Dr. Carrie Castañeda-Sound. Thank you for being such a wonderful advisor, mentor, and person. And thank you for always providing words of encouragement.

And lastly to my twin Ernesto and my husband David, thank you for all the countless hours you supported me in editing and creating a beautiful manual.

VITA

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- **Populations:** Adolescents and Adults

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Westside Regional Center
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ABSTRACT

This pilot study developed a training manual and presentation for clinicians (i.e. Service Coordinators and Psychologists) in the Los Angeles area working in community agencies, specifically Westside Regional Center, that is on the front line of diagnosis of Latino children with Autism Spectrum Disorder (ASD). The aim of this pilot study was to inform and educate clinicians on how to assist families and their child after age 3 who have been newly diagnosed with ASD. By training clinicians to be culturally responsive when engaging with families they can better assist in empowering parents over their child's ASD diagnosis. Empowered parents are more likely to use and access therapeutic services offered in the community for their child. Using convenience sampling, eleven clinicians attended a ninety-minute training/Powerpoint presentation. After the presentation, the clinicians completed a nine-item evaluation form to determine the effectiveness of the training. Feedback from the participants will be used for future editions of this training manual and presentation. Results from this pilot study suggest that clinicians would benefit from this training/presentation to engage Latino families in a culturally responsive manner when discussing their child's ASD diagnosis.

Chapter I: Introduction and Review of the Literature

Introduction

Until recently, Autism spectrum disorders (ASD) was classified as a group of neurodevelopmental disorders that impacts an individual's social-emotional functioning, communication, and repetitive/restricted behaviors (American Psychiatric Association [APA], 2000). The revision of the Diagnostic and Statistical Manual of Mental Disorder (APA, 2013) rejects the previous classifications of Autistic Disorder, Asperger's disorder, and Pervasive Developmental Disorders-not otherwise specified. Instead, the previous three domain of symptomology has been condensed into two domains: social and communication deficits and restricted and repetitive patterns of behavior, interests and activities. Severity levels, ranging from 1-3 (i.e. Level 3: requiring very substantial support), are assigned depending on the impact of their symptoms on their daily functioning (APA, 2013). The implications of these changes continue to be researched. Although this is not the goal of this study, studies comparing the two criteria thus far (e.g., Young & Rodi, 2014; Kulage, Smaldone, Cohn, 2014; Christiansz, Gray, Taffe, & Tonge, 2016) suggest some individuals will no longer meet these new and more stringent criteria.

Purpose

With such dramatic shifts in the diagnosis of ASD and growing attention on early intervention, this dissertation proposes to create a manual to support clinicians with one of the largest ethnic minority populations in the United States – Latinos. Although this population is increasingly represented in the U.S. (Pew Research Center, 2017), research with these communities is limited in the field of psychology (Bernier, Mao, & Yen, 2010). Thus, limited resources are available for clinicians working with Latinos, especially newly diagnosed with

ASD. Moreover, children with racial/ethnic minority backgrounds who receive a diagnosis of ASD often receive lower quality services than white children (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). In order to meet this need, this training manual and presentation will provide clinicians a guide to assist Latino parents and families as their child is newly diagnosed with ASD.

Autism

In March of 2016, the Center for Disease Control and Prevention (CDC) concluded that approximately 1 in 68 children in the United States have an ASD. From 2009 to 2012, the CDC concluded an average increase of 23% in identified ASD. The largest increases over time were among Hispanic children (110%) and Black children (91%). About 1 in every 68 children of Hispanic ethnicity has an ASD. It was also reported that ASD prevalence was higher among boys than among girls, ranging from more than three to six or more boys for every girl with ASD. Typically, the onset of autism occurs in two ways. Within 12 months of age, the child demonstrates some behavioral delays in social or communication development, or the child demonstrates regression of skills and abilities that were developing typically. For example, about 40% of children with an ASD do not talk at all. Another 25%–30% of children with autism can speak some words by 12 to 18 months of age and then lose the ability to speak. Potentially a third category for early onset detection was identified in children that display a plateau in social-communication behaviors in the first year and then later fails to progress developmentally over time (Ozonoff et al., 2011).

As there are no medical tests to definitely diagnose ASDs such as a blood test, clinicians must examine the child's behavior and obtain a developmental history from the child's parents to make a diagnosis (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Ozonoff et al. (2011)

conclude from their study that it is not uncommon for there to be a discrepancy between the child's behavior and what the parent observes and reports, which makes it difficult to determine the onset of autism. This observation is particularly true among children who plateau in their social-communication development early then fail to progress (Ozonoff et al., 2011). The authors suggest that parents may have difficulty perceiving and describing changing patterns in their developing child when the child's typical development is brief and atypical development is slow or fails to progress (Ozonoff et al., 2011).

Each child with autism and his or her family face a constellation of unique challenges. Not only does a child with autism typically demonstrate limitations in communication, social interaction, and behaviors, but also sensory-related behaviors that can affect everyday family functioning. From interviews with parents of children with autism, Schaaf, Toth-Cohen, Johnson, Outten and Benevides (2011) found six major themes about the family experience: (a) need for flexibility or openness to accommodations, (b) different strategies for managing familiar versus unfamiliar contexts, (c) obstacles to engaging in family activities, (d) impact of child's behavior on siblings (e.g., the child with autism monopolizing the attention from parents), (e) need for remaining vigilant of the unexpected, and (f) strategies to improve participation for the family as a whole. Parents reported limited social interactions with other families outside the home due to their child's sensory processing difficulties. Decisions about activities in which the family participates in and out of the home are dictated by the needs of their child. Most importantly, the family has to be open and flexible so as to accommodate the needs of their child in order to engage in family activities and meet family goals (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Families reported using strategies such as attending events when they were less crowded, leaving outings early, or attending events separately to accommodate for

unexpected variables in the environment that might occur and dysregulate their child (Schaaf et al., 2011). This will likely increase the families stress level.

Families of children with autism experience a higher level of stress, thus, it is important that they learn to cope successfully to ensure positive family functioning (Gray, 2006). Gray (2006) completed a qualitative longitudinal study examining how families' coping strategies change over time when caring for a child with autism. As time progressed and their child's needs changed, parents reported a decline in their reliance on coping strategies. This may be due to the parents experiencing less emotional distress over time when compared to when their child with autism was newly diagnosed. Furthermore, over time, parents may rely less on coping strategies since they have adapted to their child's routine and behavior, but not necessarily because their child's symptoms have improved. The study also found that coping strategies changed from problem-focused to emotion-focused. Problem-focused strategies include reliance on service providers, family support, and individual resources whereas emotion-focused strategies include the use of religious coping and the expression of one's feelings. It is also possible that parents place less emphasis on treatment services over time as they acknowledge the permanence of their child's disability and learn to appreciate the abilities their child does possess (Gray, 2006).

Cultural influences on the diagnosis of autism and the treatment of the disorder can vary, yet little research has been done with diverse communities coping with raising a child with autism. Thus, it is important for the research community to broaden its perspective by gaining a better understanding of different cultural experiences. For example, Bernier, Mao, and Yen (2010) reviewed cultural differences in the diagnosis, acceptance, and treatment of ASD. They indicated that it is important to focus on both macrolevel (e.g., the dominant western society's acceptance, understanding, and willingness to assist on state or national funded treatment

options) and microlevel (e.g., the familial acceptance and understanding of the diagnosis) cultural factors. The authors conclude that it is essential for clinicians and treatment providers to have insight into how different cultures may perceive autism so family traditions and cultural norms can be considered in diagnosing and treatment planning.

Disparities in ASD Diagnosis

The Autism and Developmental Disabilities Monitoring (ADDM) Network is the only collaborative network to track the number and characteristics of children with ASD in multiple communities across the United States. As noted earlier, about 1 in 68 children have been identified with ASD with a rise in ASD diagnosis in all ethnicities. However, Caucasian children were more likely to be identified with ASD than black or Hispanic (Christensen et al., 2016). Although there is an increase in early identification of ASD, there continues to be a disparity across ethnicities. In a cross sectional study implemented with data from ADDM (Durkin et al., 2017), found that those with ASD were less likely to reside in low socioeconomic status (SES) areas, and more likely to live in areas with higher adult educational achievement and higher SES. They also noted that, although the overall ASD prevalence was higher among non-Hispanic White and Asian children than among non-Hispanic Black or African American and Hispanic children, when the results were stratified by SES (i.e. low, medium, and high), there were ethnic differences in prevalence varied by SES. They concluded that if the SES gradient was due to ascertainment bias, this would imply that there are significant SES disparities in access to diagnosis and other services. It would also imply that the current estimate of ASD prevalence might be substantially undercounted, with children of low and medium SES being under-identified and underserved relative to those with high SES.

Latinos in the United States

The Latino population consists of heterogeneous groups in terms of ethnicity, physical appearance, cultural practices, traditions, and Spanish language (Santiago-Rivera, Arrendondo, & Gallardo-Cooper, 2002). Latinos are a diverse group of multigenerational immigrants from different Spanish-speaking countries as well as long-term residents. They are also diverse in terms of national origin, level of acculturation, length of residency in the United States, socioeconomic status (SES), and other demographic variables. They choose to self-identify differently, choosing various terminology that best fits. The term “Hispanic” was imposed by the U.S. Census Bureau as a pan-ethnic or umbrella term that emphasizes white European colonial heritage while excluding indigenous, slave, mestizo, and non-European and non Spanish-speaking heritages (Santiago-Rivera et al., 2002). The gender appropriate Latino/a is often used within and outside the social sciences as a “culturally inclusive” umbrella term that emphasizes roots in Latin American countries of origin. Others may simply identify as Mexican American, Cuban, Colombian, and so on. For the purpose of this study, the term Latino will be used to encompass the breadth and depth of this group in the United States.

Latino Children with Autism: Barriers to Early Diagnosis

Early diagnosis of ASD is associated with improved long-term developmental and family outcomes (Myers & Johnson, 2007). Thus, early identification and diagnosis increases the chances the child will remediate their symptoms. Typically, primary care providers are at the front line of identifying these developmental concerns. Evidence has accumulated supporting the benefits of early developmental screening for ASD as part of routine pediatric practice. However, lack of time and training has been identified as barriers to implementing routine screening.

Delayed diagnosis is a particular problem among Latino children. Latino children receive a diagnosis of an ASD two and half years later than White non-Latino children (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Williams and colleagues (2009) review the various best practice assessment guidelines and reviews of evidence-based assessment for ASD in an effort to improve diagnostic consistency across mental health agencies. Most guidelines include: (a) review of records, (b) parent interview, (c) direct observation of the child in both structured and unstructured settings, (d) standardized autism measures, and (e) assessment of cognitive and adaptive functioning (Williams, Atkins, & Soles, 2009). Despite the development of best practice guidelines for ASD assessment and the availability of standardized autism measures, in practice parents may receive conflicting diagnostic information from different professionals. A survey completed by California Department of Developmental Services (DDS) found that most psychologists assessing children with eligibility determinations for DDS were not using best practices (Hering, 2005). Further, different agencies have different goals, eligibility criteria, and assessment procedures, and even with one service system, states vary in their interpretation and implementation of Federal law regarding identification of children with disabilities (Williams et al., 2009). The same child may be considered to have ASD according to the criteria used in one system, but not to have ASD by another agency with different eligibility criteria. When contradictory conclusions about a child's diagnosis or eligibility category are made, parents are often left to sort out the conflicting information with little support from the agencies. This challenge is made even more difficult for families with less education and low socioeconomic status (Mandell & Novak, 2005).

In a study completed by Zuckerman et al. (2014), the authors note various barriers that the Latino family faces with an ASD diagnosis. Nearly all parents felt that there was little

knowledge about ASD in the Latino community and they experience mental health and disability stigma (e.g. embarrassing or shameful) in their communities. There is poor awareness of available services and lack of empowerment to take advantage of them. Some cultural basis for ASD diagnosis disparities include *machismo* (a traditional view of Latino male gender roles) with care seeking, such as being uncooperative with the diagnostic process, or taking a passive role in their child's care.

Lastly, Zuckerman et al. (2014) notes language as another barrier that families face. In their study parents expressed that limited English proficiency made every step of the diagnostic process more difficult. Language issues made scheduling appointments and arranging transportation difficult. Poor interpreter access or quality also made it difficult for parents to express their concerns and navigate the diagnostic process. As such, this will likely increase diagnostic issues and an accurate ASD diagnoses.

Diagnostic Issues

Part of the difficulty in understanding why Latinos have a lower prevalence, although increasing, may be the wide heterogeneity of features in children with ASD. Caregivers and clinicians may overlook the signs where features of ASD may be masked by cultural differences in parenting and what might be perceived as typical in terms of child outcomes such as behavior, academic performance, and language acquisition.

Williams, Atkins, and Soles (2009) found that in their study sample of 93% Latino and 76% Spanish speaking low-income children, often times there was a disagreement on whether the child had an ASD, which may be related to a number of issues. First, as previously discussed, due to different agency requirements, there can be a discrepancy on how an ASD is determined. Also, service providers were potentially not using the best practice guidelines for the assessment

of autism. Most importantly, the study found that many families were not assessed in their native language. There were 57 reports for children from non-English speaking families, and only 34 (58%) reported using Spanish. Comparing across sites, 4 out of 14 (29%) school evaluations, 7 out of 16 (44%) Regional Center reports, and 23 out of 27 (85%) Early Childhood Mental Health Program reports used Spanish when evaluating bilingual or Spanish-speaking children and families. If the parent and child are unable to communicate in their native language, the assessor is unable to properly determine if the child is meeting criteria for autism because information is misinterpreted, overlooked or missed all together. This discrepancy is also evidenced in other under-resourced communities.

Mandall, Ittenbach, Levy, and Pinto-Martin, (2007) reported that African American children with ASD were usually diagnosed with ADHD, conduct disorder, or adjustment disorder on their first specialty health-care visit. Additionally, parents from cultures that place a strong emphasis on a “respect for authority,” as in Hispanic cultures, may not question the health care provider’s practices (e.g. failure to screen for ASD), or decisions (e.g., stating that the child is fine without asking about parent concerns, or despite parent-communicated concerns). Such parent-professional interaction styles may diminish parents’ willingness to engage in an open discussion about their children’s development, which may result in deferred diagnosis of ASD or misdiagnosis.

Overton, Fielding and Garcia de Alba (2007) highlight additional considerations for research that might include investigating how parents of this minority population access health care and psychological providers for evaluation purposes and how their cultural beliefs impact this process. For example, in the geographic area of this specific study, it is common practice for some families to access their local *curandera* (folk healer) for intervention before contacting a

typical American health care provider. This practice may delay the diagnostic process. Moreover, in a dual language environment, some parents informed the authors that language acquisition was slightly delayed in their other children, or other relatives, and they did not know that this delay in the referred child was perhaps symptomatic of a developmental disorder (Overton, Fielding, & Garcia de Alba, 2007). Not only does the diagnosis process reveal some hurdles, in terms of what is developmental appropriate, but the following steps can also reveal some difficulties for Latino children with ASD.

Treatment and Potential Barriers

Early identification and treatment are essential. Once the diagnosis is made, what is preventing access to treatment? Emerging evidence indicates that once a Latino child is diagnosed with ASD they have less access and lower utilization and quality of health care compared to White children (Liptak et al., 2008; Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Parish, Magaña, Rose, Timberlake, & Swaine, 2012). Lower levels of service and less access are well documented among Latinos across different service symptoms for various reasons, including having lack of information, language barriers, fear of exposing immigration status, and few services that take into account cultural differences (Alegria et al., 2007).

Disparities in access to treatment and treatment utilization may also be tied to the availability of flexible resources, such as money, knowledge, power, prestige, and beneficial social connections. Magaña, Lopez, Aguinaga, and Morton (2013) found that White families had more flexible resources than Latino families, which may have led to a greater ability to navigate the autism service system and thus take advantage of more services for their children. Nguyen et al. (2016) concluded that families who had public insurance (e.g. Medi-Cal) to pay for ASD services were 37% more likely to have received less than 15 hours (versus greater than 25 hours)

of individual services per week than those who had private insurance. Additionally, they noted that low-income families may also have difficulty accessing services because of the additional time often required to bring to individual therapies that are not home-based, which may result in lost wages or additional transportation costs. In addition, individual intervention services may include private services that parents paid for in addition to Regional Center and school based services.

An alternative explanation involves the role of culture in health care. For example, individuals from different cultures may prefer to keep problems within the family and/or have more or less willingness to use health services. For instance, Moore and Hepworth (1994) found that despite having adequate health insurance and a regular source of care, Mexican American families used fewer maternal and child health services than other ethnic groups. Latino children have been found to have persistent low rates of mental health services use, even when controlling for other factors related to access, like socio-economic status (Alegría et al., 2004). Lau, Lin, and Flores (2012) also found that racial and ethnic minorities use outpatient and general medical health services less frequently than their Caucasian counterparts.

Level of acculturation is another factor identified by researchers. Acculturation is the process of adopting the cultural traits or social patterns of dominant group. Voelkel, LeCroy, Williams, and Holschuh (2013) delineated significant differences in the perceived barriers to care between Latinos with low acculturation and Latinos with high acculturation. Their findings revealed that Latinos with low acculturation perceive more barriers to accessing health care than those with high acculturation. They speculate that Latinos with high acculturation perceive fewer barriers to care because they can communicate more confidently in English with health care professionals and have higher English literacy, meaning that they can access publically

disseminated literature and information more easily. Additionally, although all respondents had fairly accurate understanding of the symptoms associated with autism, they had less knowledge about the etiology and course of the disorder. Their study also revealed that close to 60% of the survey participants inaccurately believed that those with autism would eventually outgrow the disorder; only 36.1% knew that autism is a primarily genetic disorder, and 46.2% believed that trauma plays a large role causing autism. They concluded that, Latino families feel that the parents of a child with ASD must have done something wrong in their parenting to somehow cause the disorder. This perception of culpability is problematic, not only because it is incorrect, but also because it connects feelings of shame and guilt to ASD such that families may be less likely to seek help because they feel that society will blame them for the problem. Zuckerman et al. (2014) found that stigma prevented parents from seeking care. Parents thought many in the Latino community perceived disabilities, and particularly mental health problems, as embarrassing or shameful. As a result, parents felt uncomfortable with their child's behaviors for concerns that others would perceive their child as mentally ill, or with an intellectual disability.

Latino Families and Children with Autism: Coping Strategies

Although Latino groups are heterogeneous, one of the common themes is *familismo*, a preference for maintaining a close connection to family, by family loyalty, unity, and support from nuclear and extended family members. In general, Latinos have a strong familistic orientation in that they value close relationships, and stress interdependence, cohesiveness, and cooperation among family members. For example, Magaña and Smith (2006) found that Latina mothers, when compared to non-Latina White mothers, reported more satisfaction with their young adult son or daughter who is diagnosed with autism and living at home. Latina mothers

endorsed higher emotional well being, lower levels of psychological distress, and worried less about relying on family for support. This is in contrast to the traditional Western view of supporting young adults towards independence from parents. Magaña and Smith's (2006) research on Latino parents of children with developmental disabilities emphasized the cultural value of *familismo* and thus Latino families are less likely to seek out support from outside the family.

Although many Latino parents hold the value of *familismo*, given the nature of ASD, parents can experience a mixed emotional experience. Parents can feel both relief and devastation (Altiere & von Kluge, 2009), relief that their child had a label for child's atypical behaviors, and devastation of the implications ASD. Altieri and von Kluge (2009) also noted that parent's emotional experience of devastation was so overwhelming that they compared it to death of a family member experiencing feelings of despair, sadness, denial, confusion, and anger. Parents also endorsed guilt and blame for potentially causing their child to have ASD. Zuckerman et al. (2014) found that some parents were very stressed and depressed following their child's diagnosis and required time to emotionally adapt. Parents also speculated that other Latino parents purposely avoided seeking out an ASD diagnosis because it would be to depressing to accept their child had a serious problem.

Despite the growing literature on families' experiences coping with their child's diagnosis of ASD, the limited research on the Latino families' experience with developmental disabilities identified religion as a coping strategy. Skinner, Correa, Skinner, and Baily (2001) examined how the role of religion is used as a support system in the lives of Mexican and Puerto Rican families when raising a child with a developmental disability (e.g., Down Syndrome, cerebral palsy, autism). The results of their mixed method study indicate that religion provides a

strong support system for a large majority of Latino families. More specifically, faith or personal religion was viewed as more supportive than the institutionalized religion, although the latter is still considered an important source of support. Faith comforted the parents on a daily basis and assisted them to view their child's disability as a part of God's plan, giving parents more confidence to move forward. As the family looks to different avenues to cope with their child's diagnosis, it is also equally important to understand the sibling's experience of ASD.

Siblings

Siblings of children with ASD or other developmental disabilities are impacted in various domains, such as their sibling role, responsibilities at home, socially, and potentially other psychological adjustments (Sharpe & Rossiter, 2002); however, much of this research has been based on Caucasian families. Thus, cultural context has been given minimal attention in research on a Latino sibling's adaptation to ASD. Mascha and Boucher's (2006) pilot study gathered subjective experiences of Caucasian typically developing siblings. Participants reported both positive and negative aspects of relating to their sibling with ASD. The majority of participants expressed positive experiences by describing their ASD sibling as fun, loving, and humorous. However, some did not note any positive experiences. Certain negative aspects were common amongst the participants, which include their sibling's aggressive and impulsive behaviors, feeling embarrassed by the behaviors, having to explain why their sibling looks "normal" and has ASD, and finally providing additional caregiving duties to help parents. Many of the negative experiences discussed by siblings are the behavioral problems often related to ASD. Siblings could benefit from learning behavioral skills to best engage their ASD sibling and ultimately enhancing their interactions and ameliorating any negative feelings.

Kao, Romero-Bosh, Plante, and Lobato (2011), found similar findings in their qualitative study examining Latino siblings' experiences of living with a child with a developmental disability. Siblings reported both positive and negative experiences similar to their non-Latino counterparts. However, they found that Latino siblings experienced significantly more internalizing symptoms and greater reluctance to express their emotions. Since Latinos share a familistic cultural value, sibling relationships and caretaking responsibilities are important while discouraging open verbal expression of sibling related distress (Canino, 2004).

In terms of adjustment, Latino children expressed less accurate information about their sibling's chronic disability compared to their non-Latino counterpart. This is likely impacted by their parent's access to information and understanding of the diagnosis. Accurate sibling knowledge of the disability was associated with greater parent (not sibling) report of sibling negative adjustment. They hypothesized that greater sibling knowledge reflected greater focus of the family resources on the child with the disability, resulting in the sibling perceiving more negative impact of the disability on their experiences (Lobato, Kao, & Plante, 2005).

It is likely that if parents are better informed about their child's diagnosis, the more accurate information is then communicated to their siblings. Ease of parent and provider communication can close this gap.

Clinician Factors

The practitioner's gender, race, and ethnicity may influence interactions with children and families from diverse populations. Matching backgrounds among clinicians and clients may contribute to increased levels of comfort and service utilization. Denney, Itkonen, and Okamoto (2007) found that Latino families of children with special needs and their health care and early intervention providers had different ideas of child needs, cultural values, and parenting practices.

These discrepancies affected parents' utilization of services and parent/provider relationship. This is very relevant when providing information regarding the client's ASD diagnosis. Despite an ethical obligation to provide psychological assessment feedback that is understandable and useful to clients (APA, 2002), little is written about psychological assessment feedback methods and outcome. Smith, Wiggins, and Gorske (2007) found that 71% of respondents ($n = 719$ psychologists) frequently provided in-person assessment feedback. Furthermore, respondents noted that feedback was understandable and accurate and that clients feel motivated to follow recommendations as a result. Also, psychologists who spent more time conducting feedback sessions were more likely to indicate positive effects, particularly as with regard to facilitating a collaborative working dialogue. With the rising prevalence and complex nature of autism and different impacts on family environments, continued research is need to evaluate the needs of Latino families and intervene where necessary. As such, clinicians would benefit from a resource to better educate and assist these children and families. Additionally, APA formally address the need for clinician's to be educated on multicultural and culture specific needs of a diverse population through the Layered Ecological Model of the Multicultural Guidelines that considers all aspects of the individual served (APA, 2017).

Summary

In summary, approximately 1 in 68 children in the United States have an ASD. The largest increases of ASD diagnosis over time were among Latino children (Christensen et al., 2016). Also, the Latino population is increasingly represented in the U.S. (Pew Research Center, 2017). With such increases, limited research and resources for families and clinicians are available discussing Latino children diagnosed with ASD. A child with ASD impacts the family in various domains of their life. As such, Latinos are a heterogeneous that does not fit neatly in

existing resources for non-Latino populations. Latino's face various barriers to early diagnosis and accessing treatment. Families have to maneuver a potentially complicated system to diagnosis when language is another barrier. Furthermore, siblings are also impacted uniquely as they are also responsible for their sibling with ASD. Since *familismo* is a strongly held value, the family's needs take priority over an individual family member's needs. Considering the unique challenges of Latino families faced with an ASD diagnosis, clinicians would benefit from information regarding the Latino population to best assist families through the ASD process.

The purpose of this pilot study is to create a training manual and presentation to assist clinicians with educating and supporting parents about ASD in a culturally responsive manner. This will also assist clinicians and families during the initial diagnosis of ASD and when transitioning to long-term case management by regional center community agencies. Parent empowerment has been identified as both a goal and an important outcome for long-term prognosis. Brookman-Fraze and Koegel (2004) suggest that an empowered parent is one who demonstrates confidence interacting with service providers and efficiency with obtaining services. Empowered Latino parents provide a wealth of knowledge, resources, and expertise, which are advantageous in accessing services for their children.

Chapter II: Methodology

This pilot study developed a training manual and presentation for clinicians (i.e. Service Coordinators and Psychologists) in the Los Angeles area working at Westside Regional Center, a community agency on the front line of diagnosis of Latino children with ASD and their families. Westside Regional Center is 1 of 21 regional centers in California. Regional centers are nonprofit agencies contracted with the Department of Developmental Services to provide or coordinate services and support individuals with developmental disabilities (i.e., intellectual disability, cerebral palsy, epilepsy, autism, and disabling conditions found to be closely related to intellectual disability) as outlined by The Lanterman Developmental Disabilities Act (“Lanterman Developmental.” 2018).

This pilot study is designed specifically to support clinicians working with children diagnosed with ASD after three years old. From birth to three years old children identified with a delay in their development (i.e. language, gross motor, fine motor, cognitive, social-emotional, and/or adaptive skills) are eligible to receive California Early Start Program services. Therapeutic services such as speech and language therapy, occupational therapy, physical therapy, infant stimulation therapy, and center-based therapy are provided until the child is three years old. At three years old a formal psychological evaluation is completed by a licensed psychologist to determine if the child meets at least a provisional diagnosis of ASD. Service Coordinators are then assigned to the child and family. Service Coordinators provide case management, advocacy, and support for the client and their respective family. Service Coordinators and families often build a strong relationship throughout the several years of working together. At least once a year Service Coordinators meet with their client and family to

discuss the child's development and needs in five domains (i.e. current abilities, social support, education, social/emotional, and health/well-being).

This chapter will describe the methodology utilized in the development of the training manual and presentation. The first phase of this study consisted of a comprehensive review of previous literature including articles from peer-reviewed journals, books, and book chapters discussing ASD, Latino children diagnosed with ASD, and the impact of ASD on Latino families when their child is diagnosed. The second phase of this study consisted of reviewing other resources and training manuals currently in circulation assisting clinicians with children diagnosed with ASD. The third phase involved integration of the collected data and development of the resource manual and presentation. The fourth phase of this study presented the training manual using a PowerPoint presentation to service coordinators and psychologists currently employed and/or contracted by Westside Regional Center in Culver City, California. The final phase of the study consisted of an evaluation of the PowerPoint presentation by clinicians (i.e. service coordinators and psychologists) currently employed and/or contracted by Westside Regional Center working with Latino young children and families in the process of ASD diagnosis or newly diagnosed.

Training Manual Development: Review of the Literature

Sources of data utilized for the literature review were collected from databases such as Psych INFO, Psych ARTICLES, ERIC, EBSCOhost, books in print, and internet resources. The review of the literature mainly focused on material related to factors related to Latino children diagnosed with ASD. More specifically, keyword searches included the following terms and phrases:

- Children with autism (e.g. Latinos and/or Hispanic and non-Latinos)

- Families coping with autism diagnosis (e.g. Latinos and/or Hispanic and non-Latinos)
- Disparities in autism diagnosis and accessing mental health resources (e.g. Latinos and/or Hispanic and non-Latinos)
- Autism screening and assessments (e.g. Latinos and/or Hispanic and non-Latinos)
- Barriers to clinical feedback (e.g. Latinos and/or Hispanic and non-Latinos)
- Acculturation and access to Autism related services (e.g. Latinos and/or Hispanic and non-Latinos)
- Autism and feedback (e.g. Latinos and/or Hispanic and non-Latinos)

Due to the recent advances in current changes of conceptualization of autism, the literature based on autism and Latino families was restricted to the year 2000 onwards unless a pivotal study was completed earlier.

Training Manual Development: Integration of the Literature

Once a comprehensive search of the literature and existing resources was completed, the researcher reviewed the information for major theme and concepts. The gathered data was integrated and organized by subject to inform the content of the proposed manual. The length of the training manual is approximately 25 pages (see Appendix A) and the information was presented in sections to provide clarity and simplicity. The training manual includes tables, graphs, and other visual images related to the content in an effort to increase the comprehension and accessibility of information. The training manual is organized in the following sections: (a) Introduction, (b) Autism: An Overview, (c) Latinos: Review, (d) The ASD Conversation, (e) Debunking Myths, (f) Empowering Parents, and (g) Resources.

Training Manual Development: PowerPoint Slides and Presentation

The manual was reformulated as a PowerPoint presentation (see Appendix B) as a means to be more accessible to clinicians. The Institutional Review Board of Pepperdine University granted permission (see Appendix C) to present the information taken from the manual to clinicians at Westside Regional Center. The researcher then collected the participants' evaluative feedback at the end of the presentation which will be discussed in the results section.

The Director of Client Services assisted with coordination of the presentation at Westside Regional Center. The total time required for the presentation was 90 minutes: 15 minutes to review and collect the consent forms, 60 minutes for the PowerPoint presentation, and 15 minutes for clinicians to complete the evaluation form. Prior to starting the presentation the participants were provided a copy of the training manual (see Appendix A), a copy of the informed consent form (see Appendix D), and a copy of the evaluation form (see Appendix E). Following this, all participants were informed of the nature and purpose of the study, the researcher's affiliation, potential risks and benefits of the study, and information related to privacy and confidentiality. The informed consents were then collected and placed in a sealed manila envelope once the participants signed them. Following the PowerPoint presentation, instructions were given to the participants to complete the 9-item questionnaire with open-ended questions related to the clarity and usefulness of the presentation (see Appendix E). The evaluations were collected and placed in a separate manila envelope.

Data Collection: Evaluation of PowerPoint Slides and Presentation

The purpose of the evaluation of the PowerPoint slides and presentation was to collect feedback from clinicians currently working with Latino families that have a child diagnosed with ASD. The presentation was evaluated on several domains that included (a) topics addressed, (b)

ease of presentation, and (c) format and visual appeal. Additionally, the participants were asked if they would recommend the presentation to their colleagues, if they found the presentation useful, areas to change and enhance, and any other additional thoughts or comments (see Appendix E).

Recruitment Strategies and Procedures

The Director of Client Services assisted the researcher to identify potential participants (i.e., clinicians) for the pilot study. Using convenience sampling, 27 clinicians were identified as individuals working with Latino families that have a child with an ASD diagnosis. An email was sent to these 27 clinicians inviting them to participate in the pilot study along with an explanation of the eligibility requirements to participate (see Appendix F). The invitation email was sent out four weeks prior to the presentation with a reminder email three days prior. The participants were encouraged to respond to the email if they were planning to attend.

Participants

Eleven clinicians elected to participate in the presentation and evaluation of the manual. All eleven participants met the eligibility criteria (see Appendix F), which stated that they are Service Coordinators working with Latino families with a child diagnosed with ASD. Participants had on average 13.8 years of experience working in this field.

Analysis of Evaluation and Completion of Training Manual

The researcher gathered and compiled the responses, following the completion of the evaluation forms. The responses gathered are integrated in the Results section of this study. The responses are discussed as areas of change, areas of expansion or enhancement, and additional comments. Feedback received from the participants will be considered for finalization of this training manual and future presentations.

Chapter III: Results

This chapter provides an overview of the content of the manual and presentation derived from the extensive literature review, and results of the evaluation by the clinicians. First, a detailed structure and content of the training manual will be presented. Second, the development and content of the PowerPoint presentation will be discussed. Finally, feedback on the presentation from the participants will be reviewed and examined.

Literature Review

Empowered Latino parents of a child with ASD have a wealth of knowledge, resources, and expertise which can assist them accessing services for their children. Additionally, an empowered parent is one who demonstrates confidence interacting with service providers and efficiency with obtaining services (Brookman-Frazer & Koegel, 2004). However, Magaña et al. (2013) found that Latino families might be limited in empowerment and advocacy skills as Latino families do not feel empowered to meet their child's needs. Keeping this in mind, the literature review was conducted to assist in creating a manual that would provide clinicians accurate knowledge about ASD to better educate and empower parents. In order for clinicians to be culturally responsive in educating Latino families, a literature review of Latino heterogeneity and cultural values was included.

Language can be a barrier for both monolingual and bilingual Latino parents. For monolingual Spanish-speakers, information available to parents is often difficult to understand due to limited or poor Spanish translation. Also, language can be a deterrent in someone's ability to access information if English were his or her second language. Moreover, health literacy is receiving information in a way that can be understood. Often medical information can be complex due to the terminology and jargon that is not easily understood. Having both limited

English proficiency and limited health literacy increased the likelihood of experiencing confusion and difficulty making sense of relevant health information or information related to their child’s ASD diagnosis (Fernandez et al., 2004). Part of the role of clinicians is to decipher the technical information found in the literature to educate families effectively regarding their child’s diagnosis and needs. This manual and presentation is part of that process to educate and empower families.

Overview and Description of the Manual

The following is a detailed description of each section of the manual. Information from the literature review was integrated into each section to develop the manual.

Section 1: The Introduction. This section is a brief review of the purpose and need of the resource for clinicians (i.e. psychologists and service coordinators) working at Westside Regional Center. This section highlights the importance of providing culturally responsive care when working with families newly diagnosed with Autism. Additionally, continuity of case management is introduced. Specifically, four sections are discussed that includes the topics: “Who should use this manual?” “What is the purpose of this manual?” “What is cultural responsiveness?” and “Continuity of case management.”

Section 2: The Autism Overview. This section includes a brief history of the diagnosis of ASD, epidemiology/prevalence rates, discussion of ASD disparities, DSM-V criteria, clinical presentation, and differential diagnosis. Strategies and skills are also discussed to assist parents engage with their child.

Section 3: Latinos Review. This section reviews the heterogeneous group of Latinos residing in the U.S. Additionally, the term “Latino” is defined in this section for the manual. The Latino Dimension of Personality Model (Arredondo et al., 2002) is discussed and provided as a

framework of clinicians when working with Latino families. Acculturation is defined and discussed as a possible impact on Latino families' knowledge of ASD and access of ASD services in the community. Lastly, shared Latino cultural strengths are defined and discussed which include: *familismo*, *personalismo*, *respeto*, *confianza*, *fatalismo*, and *plática*.

Section 4: The ASD Conversation. This section discusses how to engage Latino families when having a conversation about their child's diagnosis with ASD while incorporating cultural values discussed in the previous section. First, the process of initial feedback to Latino families is reviewed. The goal for the clinician is to engage families with the assessment process and discussion of results and diagnosis. Thereafter, clinicians are encouraged to continue the conversation with families by providing psychoeducation regarding ASD. In addition, clinicians are provided sample questions to facilitate conversations to educate and empower families with the information regarding their child's diagnosis of ASD.

Section 5: The Debunking Myths of ASD. The focus of this section is to discuss the current research in the causes of Autism and possible myths. Specifically, a brief overview of genetic, biological, and environmental factors are presented. This allows clinicians to be informed of the current research and to assist in dispelling any myths that Latino families might have about ASD. This section includes a discussion of possible myths about the cause of ASD such as the impact of learning two languages (bilingualism), *susto* (sudden fright), and poor parenting. Finally, information is provided regarding potential feelings (e.g. shame, guilt, or sense of responsibility) that Latino parents might be experiencing as a result of their child's ASD diagnosis. Clinicians can assist parents by providing research informed causes of ASD to relieve them of any possible sense of burden or responsibility.

Section 6: Empowering Parents. This section begins with exploring research on families' coping strategies when their child is diagnosed with ASD. Clinicians are encouraged to assist families as they cope with their child's diagnosis by building a strong relationship as their assigned Service Coordinator. Part of the process of empowering parents is providing families information about ASD in a manner that is jargon-free and informative. A review of potential barriers is also discussed so clinicians understand the disparity in access of services and difficulties that Latino families are facing. Finally, a variety of areas (e.g. skill-building, the value of *la familia*, self-care, and acknowledgement of accomplishments) are presented to assist families cope and feel empowered regarding their child's diagnosis.

Section 7: Resources. This section provides a list of websites and books to provide to Spanish-speaking families seeking more information on ASD. Websites were specifically chosen when the content was in Spanish or translated into Spanish. Some websites chosen were from the United States while others are from Spanish-speaking countries such as Mexico and Spain. The books added to this resource list are in Spanish and chosen to meet different needs for families such as information about autism, activities, and increasing communication.

Overview and Development of the Presentation Slides

The development of the PowerPoint presentation slides was based on the completed training manual. The slides were formatted in bullet points for ease and clarity. Charts and figures were incorporated to explain information and to further engage the participants. During the presentation, clinicians were encouraged to read the manual at their leisure to gather further information that was not necessarily reviewed or presented in detail. Due to the limited allotted time, specific slides were created to review and discuss the main objectives of the presentation.

Thirty-two slides were developed (see Appendix B) to educate and train clinicians with the objective to:

- Learn about cultural responsiveness when working with Latino families
- Learn skills to continue the conversation about ASD with Latino families
- Learn how to empower Latino parents when their child is diagnosed with ASD

Summary of the Results

Overall, the presentation was well received with mostly all positive endorsements and comments. Nine of the 11 participants endorsed *Highly Recommend* when asked, “Would you encourage your colleagues to attend this presentation in the future to help them facilitate conversations with Latino families?” One person endorsed *Might Recommend* on the same question and one did not respond. On the following question, “Overall was this presentation useful for facilitating conversations with Latino families regarding their child’s diagnosis with ASD,” nine out of eleven endorsed *Completely Agree*. One person endorsed, *Slightly Agree* to this question and one did not respond.

The participants were also asked to rate on a scale from 1 to 4, one being *Weak* and four being *Excellent* on several dimensions of “Topics Addressed,” “Ease of Presentation,” and “Format and Visual Appeal.” On average, the participants endorsed a 3.7 or higher (see Figure 1). Specifically, in the areas of “Topics Addressed”: (1a) “The presentation covered topics outlined” averaged 3.8, (1b) “The presentation covered the topics in depth,” averaged 3.7, (1c) “Order of topics was logical” averaged 3.9, and (1d) “The information was easy to use” averaged 3.9. In the areas of “Ease of Presentation”: (2a) “The material discussed was succinct” averaged 3.9, and (2b) “The speaker was easy to follow” averaged 3.9. And finally, in the areas of

“Format and Visual Appeal”: (3a) “The graphic design was engaging” averaged 3.8 and (3b) “The font was easy to read” averaged 3.9 (See Figure 1.).

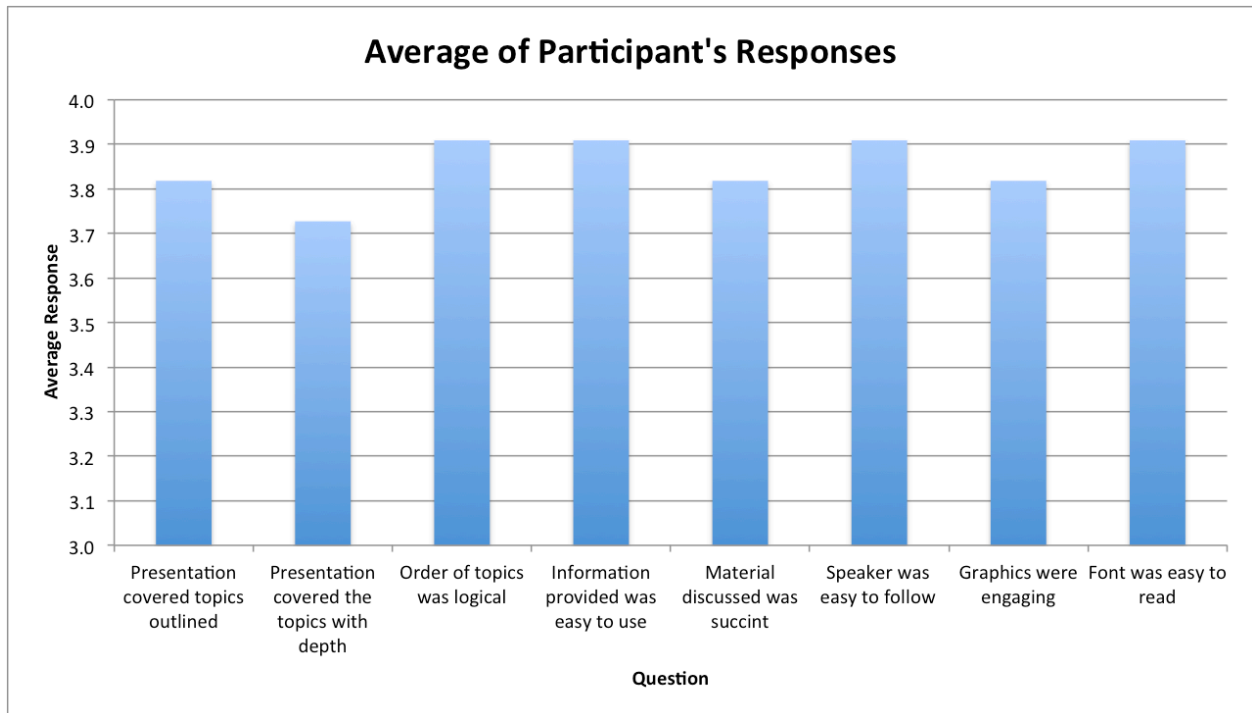


Figure 1. Average participant’s responses to the evaluation of the presentation.

The evaluation form also included open-ended questions for participants’ written feedback. The following questions were asked: “Please identify areas in the presentation you would change;” “Please identify areas in the presentation you would expand and enhance;” and “Any additional comments are greatly appreciated.”

For the first question, “Please identify areas in the presentation you would change” seven out of eleven participants provided feedback. Most were positive and some provided areas to change such as including more information on “myths” (e.g. vaccines and diet), “evidence based strategies to manage students with ASD”, and “how culture prevents families from requesting help and evaluations for their children”. One response indicated wanting less discussion on “what Autism is.”

For the second question, “Please identify areas in the presentation you would expand or enhance” eight out of eleven participants provided feedback. Two main themes in the feedback were noted that include more information on ASD and expanding on the cultural values discussion. In regards to the ASD, participants suggested more information in causes, myths, and statistics. In the feedback for cultural values, participants generally would like to have “more tips on how to interact with Latino families.”

For the third and final question, “Any additional comments are greatly appreciated” eight out of the eleven participants provided feedback. Two of the participants stated that other Service Coordinators would benefit from the presentation. Other notable feedback included the discussion of “structural/institutional issues” in accessing services by Latino families and the process in which Latino families are referred to the Regional Center.

Tables 1 through 3 present the participants responses to the open ended questions included on the evaluation questionnaire.

Table 1

Participants’ Responses to Open Response One

Participant	Participants’ Responses to Question: Please identify areas in the presentation you would change.
P1	No response provided
P2	“Nancy did a great job in explaining this to us. I would not change a thing as she covered everything.”
P3	“Honestly cannot of think anything-fantastic presentation.”
P4	“I enjoyed the presentation. I honestly wouldn't change anything”
P5	“I like the structure of the presentation. I would probably include myth relating to vaccines/diet.”
P6	No response provided
P7	“I would possibly include some evidence-based strategies on managing students with ASD.”
P8	“I might want to add more examples of how culture prevents families from requesting help and/or evaluations for their children.”
P9	“Maybe a little less discussion of what Autism is.”
P10	No Response Provided
P11	No Response Provided

Table 2

Participants' Responses to Open Response Two

Participant	Participants' Responses to Question: Please identify areas in the presentation you would expand and enhance.
P1	No response provided
P2	No response provided
P3	"Maybe more specific supports for families such as resources in community organizations, etc."
P4	"Cultural Values"
P5	"Statistics, myths causing Autism"
P6	"The cultural values portion was great. I wish there was more time to continue the discussion in that area."
P7	"I would provide greater explanations of the Autism Spectrum and what that may look like. Also, maybe additional information on causes"
P8	No response provided
P9	"I liked the tips on how to interact with Latino families. More of those kind of tips might be good if you have them"
P10	"I think the ' <i>platica</i> ' portion is very important when having a meeting of any sort with a Latino family. Not only builds trust, report, sets tone of meeting. I would provide more examples of how this can be done typically an IPP is during the birth month, so starting with birthday is a good way (What did he do for his Birthday) (What are you plans?) etc."
P11	"I would allow more time in training for those in attendance to discuss how they approach families and help them to understand the Autism diagnosis while remaining culturally sensitive and while building that trust. This could be a great dialogue where those in attendance can receive additional ideas/helps to take back with them."

Table 3

Participants' Responses to Open Response Three

Participant	Participants' Responses to Question: Any additional comments are greatly appreciated.
P1	"I believe this presentation would be very beneficial to SC's (Service Coordinators) who are Caucasian, African American, and /or New to the field of Social work in general. It applies to all parents (Latinos) with diverse disabilities, not just Autism on especially on the review on Cultural Value. I have come across families who were offended or disregarded when services were approved but vendor was neglect (would sit at family home and not do what she was there to do)."
P2	No response provided
P3	"Love this topic area as this population has been underserved! Love the cultural link and explanation"

(continued)

Participant	Participants' Responses to Question: Any additional comments are greatly appreciated.
P4	No response provided
P5	<i>“Muy buena presentación. Hace años que no había escuchado de este tema. La presentación estuvo formal, organizada, toco muchos temas interesante y concisa.”</i> English translation: Very good presentation. It has been years since I have heard a talk on this topic. The presentation was formal, organized, and touched on many interesting topics and concise.
P6	“Possibly looking at how Latino families are referred or how they find out about Regional Center.”
P7	“The information was very well organized and informative. Excellent and I'd recommend to all SC's.
P8	No response provided
P9	“Feels like when we talk about disparity we talk about the deficiencies in SC's and families, which is good to do, but we talk less about the structural/institutional issues which might be as much or more important, i.e. lack of vendors, transportation, etc. Maybe something about how SC's and families can advocate or be activists to improve the structures/institution.”
P10	“I have been providing case management to Latino families for over 12 years and I have learned many important tools during this training in order to better serve my Latino families. The discussion on "gratitude" was especially significant. I learned providing gratitude is important to a family and being acknowledged for their hard work can help meeting and the accessing of services training was extremely helpful.”
P11	“It's challenging to present the amount of information you had in such a short amount of time. I think you did a good job with that.”

Overall, the participants provided positive feedback to most questions. The participants were open to completing an objective evaluation. The feedback provided will be used to revise the manual/presentation in order to be more effective for future training. Further exploration of the comments and suggestions are discussed in the following section.

Chapter V: Discussion

The purpose of this pilot study was to develop a manual and presentation for clinicians (e.g. psychologists and service coordinators) working with Latino families with a child diagnosed with ASD. Specifically, this manual and presentation is intended to assist clinicians to empower Latino families regarding their child's diagnosis by engaging with families in a culturally responsive manner. Results from the evaluation form completed by 11 clinicians revealed that most would *Highly Recommend* the presentation to their colleagues, indicating that topic was valuable. Moreover, most clinicians also *completely agreed* that the presentation was useful in preparing them to facilitate conversations with Latino families regarding their child diagnosed with ASD. This aligns with APA's Layered Ecological Model of the Multicultural Guidelines (2017) that clinicians should be educated on multicultural and culture specific needs and as they intersect to meet the needs of our diverse population.

Identified Areas of Change of the Presentation

The clinicians that reviewed the presentation, as assessed by their responses in the evaluation form, reported mostly positive feedback. Participants that commented on areas of change requested to include more information regarding Autism diagnosis myths such as vaccinations and diet. In 1998, Wakefield and his colleagues made claims that the measles-mumps-rubella (MMR) vaccination was linked to ASD. Although this study was later retracted (Murch et al., 2004), anecdotal evidence from clinicians suggest that families continue to lean on this claim. Moreover, gluten and casein-free diets have not shown to reduce behavioral symptoms in children diagnosed with Autism (Navarro et al., 2015). This illustrates the importance of clinicians having the most updated research findings on ASD to appropriately inform and educate families.

Another participant requested information regarding evidence based strategies to manage students with ASD. This suggests that parents might feel that they may lack some ASD specific skills to engage with their child. It is possible that a parent might feel more empowered about their child's diagnosis if they also possess skills to engage with their child such as learning how to encourage eye contact, playing appropriately with toys, and/or reducing stereotypic/repetitive behaviors. Many children are eligible for applied behavioral analysis (ABA) services and support services in schools through their Individualized Education Plan (IEP). The degree of involvement of parents varies in the process of (a) identifying the child's needs (b) selecting an appropriate behavioral therapy/approach, and (c) understanding the foundational skills that are being taught to their child. For a parent, it may appear that the therapist is playing with their child but the therapist may be teaching their child appropriate eye contact, social/relational skill building, turn taking, and appropriate social conversational skills. The Early Start Denver Model (Rogers & Dawson, 2009) can be an adjunctive therapy to assist parents in the home alongside other therapies to refine skills that parents may already be engaging in without their knowledge. Families can greatly benefit from such training, however this is out of the scope of this pilot study.

Finally, one participant requested more information on "how culture prevents families from requesting help and evaluation for their children." Due to the time restraints, barriers to treatment were briefly discussed but reviewed more in depth in the manual. There are several factors that can impede families from requesting help and/or seeking an evaluation for their child. Some notable factors include limited English proficiency, lack of awareness of services, and lack of empowerment to take advantage of services (Zuckerman et al., 2014). As Magaña and colleagues (2013) concluded in their study, clinicians can meet the needs of these families by

providing them with greater awareness and knowledge about ASD and the services that are available to them.

Identified Areas of Expansion or Enhancement of the Presentation

Two main themes in the feedback from the participants noted further discussion on ASD and cultural values. As stated earlier, the presentation was limited in terms of time which restricted the ability to discuss at length each section in the manual. However, the participants were urged to review the manual at their leisure for more in-depth information on items that were reviewed briefly. With that said, a participant suggested more information regarding causes, myths, and statistics about ASD, all items that were reviewed in the manual. Although more information was requested on ASD, participants were noted to be less engaged during that part of the presentation. Due to the nature of the foundational material it does not lend itself to be more interactive and as interesting. However, the foundational material on ASD is vitally important so that clinicians have the correct information in order to appropriately educate families on the ASD symptoms and behaviors, demystifying stigma, and debunking myths.

In terms of the suggestion to expand on cultural values, two participants noted this request. Specifically, one participant wrote requesting “more tips on how to interact with Latino families.” During the presentation and subsequent discussion of cultural values, several anecdotal stories were used to highlight how some cultural values might be expressed. The participants were visibly more engaged during this time highlighting their interest. Expanding the time for discussion would allow for further exploration on how clinicians could practice these skills during the training providing them with the skills to be culturally responsive when engaging with Latino families.

Additional Comments Provided about the Presentation

The last question on the evaluation form asked clinicians to add any additional comments. The purpose of this question was to allow participants to provide feedback outside of the formal evaluation questions. Two participants suggested that “other Service Coordinators would benefit from the presentation.” This study’s purpose was to pilot the presentation selecting only Service Coordinators working with Latino children diagnosed with ASD and their families. While 11 participants of the 27 invited attended, the remaining 16 would also benefit from attending this training. Additionally, Westside Regional Center also has Service Coordinators working with other ethnicities and diagnoses (e.g. cerebral palsy and intellectual disabilities). Although this study did not discuss other diagnoses and cultural values of other ethnicities, it is possible that similar principles can be applied when working with Latino families and other diagnoses. This is an area that deserves more attention for future studies.

Another notable comment by a participant was the “discussion of structural/institutional issues in accessing services by Latino families and the process in which Latino families are referred to the Regional Center.” The purpose of this study is to empower parents to access services and be active advocates for their child, but this participant highlights that other factors may be impacting disparities of services available in certain geographical areas. It is not uncommon for clients of WRC to have difficulty in accessing providers (i.e. occupational therapy, speech therapy, social skills) that are in their native language and/or in lower SES areas. If parents are already limited in their resources (i.e. transportation, financially), they will have difficulty seeking services outside of their local area. This would potentially require taking time off from work, arranging childcare for their other children, and arranging transportation to and from the provider’s location. In a study completed by Buesher, Cidav, Knapp, and Mandell

(2014), found that the diagnosis and treatment for ASD ranges from \$1.4 million (without an intellectual disability) to \$2.4 million (with an intellectual disability) over the person's lifetime. This also included the parent's loss wages suggesting that families already struggling financially can be impacted more severely. Although this is outside the scope of this study, these identified barriers require further exploration to determine how to increase supports for families and make accessible of services (e.g. social skills, ABA therapy) in the lower socioeconomic strata.

Finally, although not documented on the evaluation form, the concept of acceptance was brought up during the discussion after the presentation. A participant inquired about assisting families to "accept" that their child is diagnosed with ASD. The participant stated "if parents accepted the diagnosis" they would be more likely to engage in services and be active in their child's treatment plan. The concept of acceptance was not specifically reviewed in the manual and presentation, but positive and negative coping strategies were discussed. Avoidant coping was found to be harmful to parents whereas positive reframing of a stressful event was the most effective coping strategy (Hastings et al., 2005). Some Latino parents "accept" their child's diagnosis as "God's will" (Voelkel et al. 2013). Weiss, Cappadocia, MacMullin, Viecili, and Lunksy (2012) found that greater acceptance of difficult emotions and thoughts was associated with lower levels of psychological distress and greater levels of parent empowerment. Additionally, positive coping was associated with more optimism and lower levels of depression (Willis et al., 2016). Furthermore, understanding ASD behaviors and symptoms as they relate to the child is important. However, it is more imperative that parents accept their child for their unique strengths and weaknesses to better assist their child's needs and to increase parent's overall emotional wellbeing. In a study completed by Altieri and Von Kluge (2009), noted a father's initial loss of hope stating, "I am starting to accept that he will not be typical." Once the

father accepted his child unique abilities, hope eventually returned. The family was able to seek out services and become confident and effective advocates by increasing their knowledge about ASD.

Limitations and Recommendations for Future Steps in Program Development

This study received several positive comments but the most notable limitation to this study was the time constraint for the presentation. The presentation itself was 60 minutes and would have benefited from additional time over additional training sessions. Feedback indicated that participants were eager to learn more in-depth information regarding ASD and culture informing their conversation with Latino families. Additionally, the participants were given the manual prior to the presentation to follow along and they were encouraged to read at their leisure. The study would have further benefited from an evaluation of the training manual to improve its user-friendliness. Another limitation to this study was the sample size. Although the sample size was as proposed and targeted towards clinicians, having more participants from different fields (e.g. psychologists and social workers) could inform the applicability of this study across disciplines. Lastly, the presentation would benefit from changing some of the language to be more strength based versus language that infers a negative connotation.

Recommendations for Future Steps

Based on the above-mentioned recommendations, the following are possible modifications to the next revision of the presentation that could strengthen it:

1. Changing the format from a presentation training to a workshop- making it an interactive training rather than passively listening to a presentation.
2. Making the presentation longer and in three sessions (a) ASD information review, (b) Latinos review, and (c) Application of concepts.

3. Address areas of acceptance of child's strengths versus the child's diagnosis as a deficit in areas of coping.
4. Change language of power point slides to be more strength based such as, "Cultural Values" to "Cultural *Strengths*" and "Who's at fault?" to "Who's *Not* at Fault."
5. Evaluation of the training manual.
6. Evaluation of the presentation and manual by a variety of clinicians (e.g. psychologists, social workers, etc.).

Conclusion and Implications of this Study

The training manual and presentation was developed to assist clinicians empower Latino families when their child is diagnosed with ASD. The training manual and presentation were developed from existing literature to create a culturally responsive dialogue with Latino families regarding ASD. The presentation was evaluated by 11 clinicians working at Westside Regional Center who are at the forefront of children being diagnosed with ASD. These evaluators provided feedback regarding areas of change, enhancement, and expansion. All responses and comments were reviewed and considered in terms of inclusion in future drafts of the training manual and presentation. Additionally, as research continues and feedback is received the manual should also evolve over time to meet the needs of the population. The intention of this pilot study was to help reduce the disparities in the access of ASD diagnosis, treatment, and services offered at Westside Regional Center. Moreover, by properly training clinicians they can have the appropriate skills and abilities to be culturally responsive when working with Latino families.

This researcher was encouraged by the increase of literature focusing on Latino families and their experience with ASD. There is still much to learn to support Latino families but I hope others continue to broaden this area of research.

The process of creating this manual was a balance of including as much foundational information while still making the manual user friendly and applicable. The main focus was on how a Service Coordinator could benefit from the information and also easily translate the information to educate families. The Service Coordinators' enthusiasm during the presentation confirmed the purpose of this study and the need for continued research with Latino families and children with ASD diagnosis.

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APPENDIX A

Training Manual

Training Manual for Clinicians:

The CONVERSATIONS

with Latino Parents after An ASD diagnosis

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INTRODUCTION

Who should use this manual?

Clinicians (e.g. Psychologists and Service Coordinators) at Westside Regional Center (WRC) are at the forefront working with Latino parents and their children newly diagnosed with Autism Spectrum Disorder (ASD). Current research, skills, and tools are ever evolving and it is imperative that clinicians stay informed in order to increase their knowledge to ultimately empower the client and respect their families. This manual is to help clinicians gain the knowledge and skills to support families when their child is newly diagnosed with ASD. Ultimately the goals are to successfully engage parent and to empower them with knowledge, strategies, and skills to support their child diagnosed with ASD.

What is the purpose of this manual?

This manual is to help clinicians gain the knowledge and skills to engage and support families when their child is newly diagnosed with ASD by empowering parents with knowledge, strategies, and skills to support their child newly diagnosed with ASD. This manual will equip clinicians with the tools and skills to have the appropriate conversation with these families. Additionally, the purpose of this manual aligns with the mission statement that WRC holds “to empower people with developmental disabilities and their families to choose and access community services that facilitate a quality of life comparable to persons without disabilities.” Additionally, this manual supports the need to close the gap on the disparities of services by ethnic minorities at WRC.

What is cultural responsiveness?

Cultural responsiveness is the ability to learn from and relate respectfully with people of your own culture as well as from others. As clinicians helping children and families we must tailor our approach to educate and empower families that will be the most effective. Disparities in the access of services are very present at Regional Centers for Latino families. Using culturally responsive adaptations to inform, educate, and support families is a means to close the gap of disparities in access to care.

Continuity of Case management

The initial meetings are just as important as future meetings with families. During the initial meetings, this provides an opportunity to help parents understand their child’s diagnosis and the possible impact on the family. As the child develops his/her needs changes, their personality changes, and their case management needs change. Clinicians should be equipped for the ever-evolving conversation of the client with ASD and their family.



AUTISM OVERVIEW

History of Autism

As early as 1747, there have been documented accounts of individuals described to have symptoms that include lack of awareness, rigid thought process, bizarre behaviors, and insensitivity to pain (Frith, 1989). Leo Kanner used the term autism when he introduced the label early “infantile autism” in his 1943 study of 11 children with behavioral similarities in his landmark study entitled “Autistic Disturbances of Affective Contact” noting an early onset usually prior to 30 months (Woo & Keatinge, 2016). Among his study participants, Donald Triplett was the first person to be diagnosed with autism in 1938 and was labeled as “case 1”. Around the same time as Kanner, a Viennese child psychiatrist named Hans Asperger, submitted his thesis in 1944 studying similar children titled, “Autistic psychopathy in childhood” (Lyons and Fitzgerald, 2007). Asperger’s study was later used in 1981 by Wing (1981) to discuss adults diagnosed with “Asperger’s syndrome.”

Misconceptions about autism have led to decades of confusion when the term was used to describe infantile schizophrenia or as a response to cold and rejecting parents called “refrigerator parents” that supposedly caused their child to withdraw into their own worlds (Siegal, 1996). Not until 1980 did the Diagnostic and Statistical Manual of Mental Disorders-III (DSM-III; American Psychiatric Association [APA], 1980) differentiate autism as a unique clinical diagnosis from childhood schizophrenia. In 1987, the DSM-III revised and replaced Infantile Autism with Autistic Disorder (APA, 1987). As research continues and advances in technology are made, our understanding of Autism continues to grow and the diagnostic criteria of Autism has been expanded and refined. In 1994, The Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV; APA, 1994) revised the diagnostic criteria to include five subtypes of autism including Autistic Disorder, Asperger’s Disorder, PDD-NOS, Rett’s Disorder, and Childhood disintegrative disorder. However, with a major shift the fifth edition of The Diagnostic and Statistical Manual of Mental Disorders-V (DSM-V; APA, 2013) has now collapsed the subtypes into a single disorder of Autism Spectrum Disorder (ASD). In Spanish, Autism is referred to as *Autismo* and also *Trastorno del Espectro Autista (TEA)*.

Epidemiology/Prevalence Rates

The Autism and Developmental Disabilities Monitoring (ADDM) Network community report funded by the Centers for Disease Control and Prevention (CDC) estimates 1 in 68 children have been diagnosed with autism spectrum disorder (Christensen et al., 2016). This is 30 percent higher than previous estimates reported in 2012 of 1 in 88 children. Estimated prevalence was four and a half times higher among boys than among girls, estimating 1 in 42 to boys compared to 1 in 189 girls. Most children are diagnosed after the age 4. White children were more likely to be identified with ASD than Black or Hispanic children. Black children were more likely to be identified with ADD than Hispanic children. It is estimated that there are currently between 500,000 and 1 million children aged 6-17 living with ASD in the United States (Christensen et al., 2016).

AUTISM OVERVIEW

Disparities

Research does not demonstrate that Black or Hispanic children have a lower risk of developing ASD than White children. The CDC (Christensen et al., 2016) estimated prevalence rates among Hispanic children was lower (10.1 per 1,000) when compared to non-Hispanic White children (15.5 per 1,000) and non-Hispanic Black children (13.2 per 1,000). It is possible that many face socioeconomic or other barriers resulting in lack of delayed access to evaluation, diagnosis, and services. Some studies have shown that stigma, lack of access to healthcare services due to non-citizenship or low-income, and language barriers are potential factors that influence ASD identification among Hispanic children. A study completed by Zuckerman et al. (2013) found that Latino parents' perspectives of barriers to diagnosis included community knowledge and perception of ASD, parent and family factors such as limited English proficiency, lack of awareness of services, low income, and lack of empowerment to take advantage of services further complicated by families with mixed immigration status, and health care system barriers (e.g. dismissing parental concerns, too difficult to navigate). Moreover, lack of awareness of ASD is common in Third World countries (Zuckerman et al., 2014). It is possible that their lack of knowledge in ASD continues when these families immigrate to the WRC's catchment area. This lack of awareness, learning to navigate a new system can likely impact their ability to access services. A study found that Latino children with ASD used school-based services similar to White children, however they were less likely to use publicly funded community based services than White children (Magaña et al., 2013).

WRC gathered feedback from members of the community in two public meetings on March 7, 2016 and March 12, 2016 to address the statistical disparity in the purchase of services of clients by ethnicity, language, age, and diagnosis (Westsiderc.org, 2016). The audience in attendance included (7) clients, (26) family members of clients, (6) WRC staff, (2) vendors, (1) state council member, (1) board member, (4) service providers, (2) disability rights of California staff.

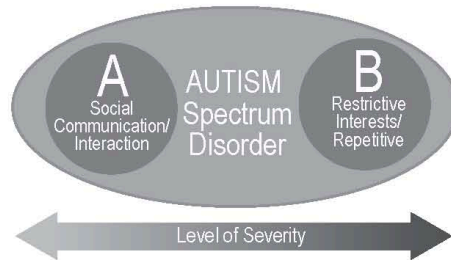


Feedback from the public meetings note that there is a lack of awareness of services that impacts parents not using 100% of the services offered. Additionally, the audience indicated that the service coordinators would benefit from more training to assist their client's and families. It was also noted that Spanish-speaking parents were not present for the first meeting. It was not clear as to why parents did not attend but possible reasons have been noted in the research highlighted above (e.g. limited English proficiency, previous experiences in feelings of dismissal).

AUTISM OVERVIEW

DSM V Criteria for Autism Spectrum Disorder

ASD is a biologically based neurodevelopmental disorder that has been revised from a three-domain model to a two-domain dimensional approach. According to the DSM-V the two domains are Social Communication/Social Interaction and Restricted Interests/ Repetitive Behaviors. The onset of symptoms must appear in the child's early developmental period. However, symptoms may become apparent when social demands exceed the child's capacities (APA, 2013).



A. Persistent deficits in social communication and social interaction across multiple contexts (specifying current severity)	B. Restricted, repetitive patterns of behaviors, interests, or activities by at <u>least two</u> : (specifying current severity)
<p>A1. Deficits in social reciprocity: abnormal social approach and failure of normal back and forth conversations, reduced sharing of interests, emotions, or affect, failure to initiate or respond to social interactions.</p> <p>A2. Deficits in nonverbal communicative behaviors used for social interaction: poorly integrated verbal and nonverbal communication, abnormalities in eye contact and body language, deficits in understanding and use of gestures, total lack of facial expressions and nonverbal communication.</p> <p>A3. Deficits in developing, maintaining, and understanding relationships: difficulties adjusting behavior to suit various social contexts, difficulties in sharing imaginative play or in making friends, absence of interest in peers.</p>	<p>B1. Stereotyped or repetitive motor movements, use of objects, or speech: simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases</p> <p>B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior: extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day.</p> <p>B3. Highly restricted, fixated interests that are abnormal in intensity or focus: strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests</p> <p>B4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment: apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement.</p>

AUTISM OVERVIEW

What does that look like?

ASD is a spectrum disorder meaning that no two children will have exactly the same symptoms or behaviors. With that said parents might be confused about their child's diagnoses due to their severity of symptoms when compared to other children with ASD. Also, as the DSM-V criteria outlines, a level of severity (e.g. "Level 1 requiring support" to "Level 3 requiring very substantial support") is identified to further explain the impact of the child's diagnosis (APA, 2013). Symptoms can be mild to disabling. The DSM-V provides five additional specifiers to further explain the clinical presentation that include whether the individual has a intellectual impairment, language impairment, a known medical condition, another diagnosis, and/or with catatonia (APA, 2013). Individuals with ASD can also face difficulties with motor dysfunction, clumsiness, and eating or sleeping problems (Woo & Keetinge, 2016). A child will likely have a wide range of skills sets that include different strengths and difficulties. ASD is a lifelong condition that will be likely change throughout the person's lifetime and in relation to the support they are accessing.

Although we understand ASD to be a lifelong condition, there is a subset of children that lose or no longer meet criteria for ASD. Helt and colleagues (2008) determined that between 3 and 25 percent of children appear to lose their ASD diagnosis and demonstrate functioning in the average range of cognitive, adaptive, and social skills. Moreover, some predictors for better prognosis included relatively high intelligence, earlier age of diagnosis and treatment (Helt, 2008). Fein et al. (2013) determined that children who are treated as infants or toddlers make the most progress and 1 in 10 have been described as recovered or have achieved "optimal outcome". However, in a follow up study of children who "recovered from autism" after early intervention the majority continued to need support 3 to 4 years later (Olsson, Westerlund, Lunstrom, Giacobini, Fernell & Gillberg, 2015). Other reasons for a child losing their diagnosis include misdiagnosis, difficulty differentiating health conditions and other developmental delays, and/or a child may receive an ASD diagnosis as a placeholder to receive services which is then later removed (Blumberg et al., 2016).

AUTISM OVERVIEW

What if it is not Autism?

In the process of a psychological evaluation, an important step is to determine if there is underlying medical condition that may be causing the individual's symptoms. Approximately 5 to 33% of individuals with ASD also had Rett's Disorder, Fragile X syndrome, tuberous sclerosis, cerebral palsy, and/or a central nervous system disease (Woo & Keatinge, 2016). These medical conditions present with similar autistic-like symptoms but with a medical origin of cause.

Other diagnoses have some similarities to ASD but can be differentiated by their specific criteria. Such diagnoses include intellectual disability, global developmental delay, social communication disorder, and attention deficit/hyperactivity disorder (Woo & Keatinge, 2016).

Intellectual disability is defined in the DSM-V by deficits in the two areas of intelligence and adaptive functioning. Onset occurs during the developmental period (before 18 years old). The individuals social functioning is consistent with their intelligence quotient (IQ) and impairment in gaze, eye contact, and play are not noted.

Global developmental delay is diagnosed under the age of 5 (APA, 2013) and delays are found in several areas of intellectual functioning. This diagnosis is provided when the individual fails to meet expected developmental milestones and cannot be reliably assessed, whereas a child with ASD can be evaluated before 24 months.

Social communication disorder (SCD) is characterized by deficit in the social use of language and communication. This is manifested as deficits in social communication, language, delayed speech, and processing. They have difficulty taking turns in conversations, understanding and making inferences, and nonliteral language (APA, 2013). Although SCD has some shared characteristics with ASD, their deficits are specific to communication. An individual with SCD does not demonstrate restrictive and repetitive behaviors and there is no regression of language as seen in ASD.

Attention Deficit/Hyperactivity Disorder (ADHD) is a persistent pattern in attention and/or hyperactivity-impulsivity that interferes with functioning or development (APA, 2013). Similar to ASD, they are distracted or at times overly focused. They have tantrums, are impulsive, and they have some social dysfunction. However, they demonstrate social reciprocity and their play skills are intact. Individuals with ADHD fidget and are restless but do not demonstrate restricted repetitive behaviors or sensory difficulties.

AUTISM OVERVIEW

Strategies to Assist Parents for Positive Outcomes

There are many challenges that parents face raising a child with ASD. As such, it is important to understand how ASD impacts their child individually as their needs will likely be different than any other child with ASD. Rather than focusing on the deficits a parent can practice acceptance by embracing their child's strengths and building on their successes. Here are some strategies to assist parents embrace and build on their child's strengths.



Schedule

Create a routine/structure of your daily activities (i.e. wake up, brush teeth, change clothes, make breakfast, and etc.)



Consistency

Use techniques learned in a variety of settings not just during the therapy session or at school.



Praise

Provide positive words of praise when they act appropriately or use a new skill. Catch them when they are doing good and not necessarily in a structured activity.



Observe

Observe the non-verbal cues that your child may be expressing to communicate their needs (sounds, facial expressions, gestures). Observe any sensory sensitivities (light, sound, touch, taste, smell) to understand better what your child enjoys or finds uncomfortable.



Engage

Play with your child by using a preferred toy, provide eye contact, and describe your interactions (the blue car is driving down the road and it bumped into the white bunny).



Model

Demonstrate appropriate reciprocal social interactions by turn taking, sharing and using appropriate language.



Play

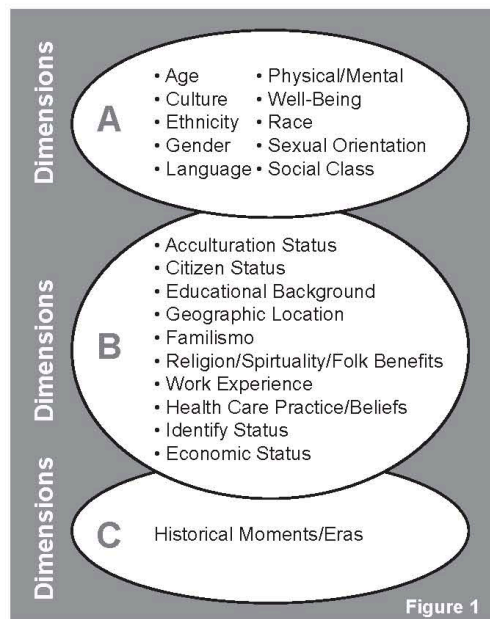
Allow time to for fun in outdoor or indoor activities that your child enjoys. Running in the park, jumping, swinging on the swings, playing an instrument are just some examples to have fun and create meaningful memories.

An individual diagnosed with ASD can lead a very successful life. As with any child, it is impossible to predict the possibilities for their future. By actively engaging in their child's treatment, parents can assist in generalizing positive behaviors across various domains (i.e. school, home, park, therapy) to help them learn and have more efficacious interactions with others. Families can also build on their child's interests (i.e. video games, history, comic books, singing, gymnastics, art) to facilitate mastery and encourage positive self-esteem.

LATINOS: REVIEW

Latinos/Hispanics represent the largest racial ethnic minority population in the United States of America and one of the fastest growing ASD populations (Pew Research Center, 2017). Yet, Latinos demonstrate lower prevalence rates of ASD according to the latest CDC surveillance study (Christensen et al., 2016). As of March 2017, WRC reported that Hispanics are the largest ethnic group making up 33% of their current caseloads. White clients make up 29% and Black/African American clients make up 22% (Westsiderc.org, 2017).

The term Hispanic refers broadly a group of people who originate from Spanish-speaking countries, regardless of race or ethnicity (US Census Bureau, 2010). As a consequence of this broad label it leads people to believe that Spanish-speaking people from various countries all have one common culture, while the term refers to a racial category for bureaucratic purposes. The term Latino is more representative of people from Latin America who have indigenous roots. Thus, the term Latino will be used in this manual. With that said there are considerable differences within- and between- Latinos. One cannot assume the sameness about the different ethnic groups- such as Colombians, Hondurans, Guatemalans, and Mexicans.



As noted by Santiago-Rivera, Arrendondo, and Gallardo-Cooper (2002) these groups all have different histories, socio-political influences, forms of government, and mental health agendas. Additionally, though there is a shared language there are varying levels of education, migration histories, acculturation, and socio-economic levels. Using the Latino Dimension of Personality Identity Model (Figure 1.; Santiago-Rivera, Arrendondo & Gallardo-Cooper, 2002), clinicians are provided a framework to better understand the individual and family Latino experience holistically.

LATINOS: REVIEW

Through the use of this model clinicians can gather knowledge about the family instead of making assumptions based on the families' visible ethnic identity. Moreover, "culturally competent counselors 'can identify specific attitudes, beliefs, and values from their own heritage and cultural learning that support behaviors that demonstrate respect and valuing of differences' (Santiago-Rivera et al., 2002, p. 16) as it relates to the individuals and families served by WRC. This framework can better inform clinicians how to adapt and approach families based on the different dimensions highlighted in the model in order to address and empower families over their child's ASD diagnosis.

Acculturation

Acculturation is the ongoing and dynamic process in which an individual, group, or people adapt or merge their cultural practice as a result of prolonged contact with the dominant culture. Each individual's level of acculturation can differ. Moreover, Latinos can be greatly impacted by their acculturation process. A study conducted by Voelkel, LeCroy, Willimas, and Holschuch (2013) found that Hispanics with low acculturation perceived more barriers to accessing health care than those with high acculturation. This is likely due to high acculturation individuals having higher English literacy, meaning they can better communicate to healthcare professionals and can access publicly disseminated information more easily. While low acculturation Hispanics have less exposure to autism, have read less about autism, and personally do not know someone with autism.



LATINOS: REVIEW

Cultural Strengths

In light of the above stated differences within the Latino community, there are also common elements that creates a group identity beyond a shared language. These values include *familismo*, *personalismo*, *respeto*, *fatalismo*, and *platica*.

Familismo

Familismo "is usually described as including a strong identification and attachment of individuals with their families (nuclear and extended), and strong feeling of loyalty, reciprocity, and solidarity among the same family" (Triandis, Marín, Betancourt, Lisansky, & Chang, 1982). For example, this can be seen in assisting with caregiving duties, financial assistance, emotional support, and problem solving. The family is committed to each other as a collective unit versus an individual person. Additionally, Sabogal, Marín, Otero-Sabogal, Marín, and Perez-Stable (1987) found that highly acculturated families continued to remain strong in their value of *familismo*. Thus, Latino families that have immigrated and are living in the U.S., while integrating American customs and values, continue to value the collective family unit as a support system for each other.

Personalismo

Personalismo is the emotional investment in the family and the development of warm, friendly, and meaningful interpersonal relationships with others (Santiago-Rivera et al., 2002). For example, when visiting a Latino's home they might offer you a drink and/or snack to make you comfortable in their home. Or, if you share that a family member is sick they might offer to pray for them.

Respeto

Respeto (respect) is an understanding on how familial and interpersonal relationships dictate informal or formal communication toward others on the basis of age, gender, authority status, and socioeconomic status, creating relational boundaries (Gallardo, 2012). This can be seen in the Spanish language when using formal or informal use of pronouns such as *tu* and *usted*. A younger individual would address the elder individual with formal language always out of *respeto*. Additionally as a professional working with a family, formal language would be used. This can also include asking permission or with an apology to inquire about the family's or child's history (e.g. Please excuse me, but I need to ask you some personal questions...).

Confianza

Confianza (trust) is the needed to develop interpersonal and professional relationships. *Confianza* creates a safe place for Latinos to be more open and share information they would otherwise feel uncomfortable to talk about (Santiago-Rivera et al., 2002). For example, a mother may have *confianza* with an individual if she is open to sharing her concerns about her child's development.

Fatalism

Fatalism is the belief that some things are meant to happen. These events can be positive and/or negative and they are out of one's control. Umezawa et al. (2012) found that Hispanics relied on positive religious coping where the belief in divine control was related to positive reframing, planning, and active coping. The participants in the study saw their struggle with a negative event as a necessity in order to remain devout followers in their religious faith.

Platicar

Platicar is known as "small talk." *Platica* is connected to the value *personalismo* and it is a form of conversation that eases and engages Latinos into an environment of familiarity (Santiago-Rivera et al., 2002). This light conversation, possibly checking in on the weather or sharing some personal news demonstrates your investment in the individual or family (e.g. *personalismo*).



THE AUTISM SPECTRUM DISORDER CONVERSATION

Feedback

The initial feedback to parents is a necessary step as the child and his/her parents have invested several hours and possibly days of their valuable time to have a thorough psychological evaluation completed. Receiving a diagnosis of Autism for their child can be very stressful and overwhelming for parents. The process of feedback can further create or solidify any positive or negative thoughts or feelings about healthcare professionals in general if families are disconnected from the process of receiving feedback. If parents are adequately informed of their child's diagnosis at the outset, parents can feel supported and empowered to participate in the ongoing conversation about their child's diagnosis, treatment, and future. Two key components of a successful feedback session are: personal connection with the family, a feeling that the clinician genuinely cares (*familismo*) and an open and honest clinician (*personalismo*; Osborne & Reed, 2008; Hasnat & Graves, 2000).

Building a relationship with the family begins at the outset of the evaluation. Beginning with formal language in greetings to indicate *respeto* for the family, such as "*gracias por haber venido y su tiempo, Sra. Guardado*" ("thank you for coming and your time, Mrs. Guardado"). Additionally, building in time for *platica* is recommended to talk about other aspects of the family's life to enable a comfortable setting. Since clinicians are seen as authority figures out of *respeto*, Latino families may not question the purpose for the evaluation. Therefore, families should be explained in the appropriate language why their child is being evaluated and what assessment will be used (*personalismo*). Families should be encouraged to ask questions, offer observations, and provide information anytime during the evaluation to facilitate *familismo*. Throughout the process of the clinical evaluation the family is building *confianza* with the clinician. Additionally, this is setting the stage by modeling and teaching behaviors of engagement with professionals for possible future encounters.

When scheduling the feedback session, provide the family an opportunity to invite other family members or friends who may provide support (*familismo*). The feedback session should begin greeting the family warmly and the continued use of formal language until the family indicates otherwise. Parents should be acknowledged for pursuing the evaluation, following through with their appointments, and providing observations. The clinician can note any of the similar or dissimilar observations from the parents. This facilitates *personalismo* when the parents' observations are validated and acknowledged as necessary for the child's evaluation. Finally, the use of clear, direct, and straightforward language is important when discussing the diagnosis. The clinician should respect the family's stage of acceptance in receiving their child's diagnosis. However, as indicating earlier, the family may not ask questions out of *respeto* and accept the results on face value. Parents should be encouraged to ask questions about any thoughts, concerns, or fears related to their child's new diagnosis. The session should end on a positive note by reflecting on the child's and family's strengths and positive attributes to encourage optimism and hope.



THE AUTISM SPECTRUM DISORDER CONVERSATION

Although this is a sample feedback process with a family, using the Latino Dimension of Personality Identity Model (Santiago-Rivera et al., 2002) as a framework can guide how to modify the feedback and future conversations. For example, depending on the family's level of education, English proficiency, language literacy, and language preference may determine the use of language style (e.g. English, Spanish, language switching, Spanglish) and grade level of language (e.g. simpler versus highly technical terms).

Continue the conversations

After the initial feedback session several different scenarios could be occurring with the parents. It could be that parents were aware of the child's symptoms and had already suspected ASD. Or, the family was unaware what was occurring with their child's behaviors and the diagnosis of ASD was a complete surprise and parents' are still unsure what ASD is. In order ensure that parents and families are adequately informed of their child's diagnosis, it is best to assume a position of not knowing and honest curiosity to determine how knowledgeable parents are of ASD. Listed below are some questions to consider when meeting with parents and families for the first time that facilitates *familismo* and *personalismo*.

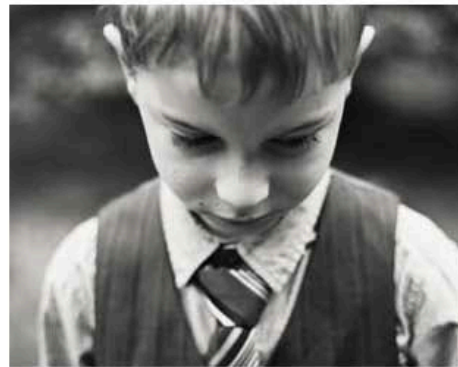
- What is important to your child and family?
- What are your priorities to address first?
- When did you first have concerns for your child? (Was it another person that expressed concerns?)
- Has your child ever received any therapies to help with the concerns expressed?
- How was the process of psychological testing?
- Did you meet with the psychologist for feedback?
- What is your understanding of Autism Spectrum Disorder?
- What is your family's understanding of Autism Spectrum Disorder? Are they supportive? Do you feel comfortable telling your family and friends?
- How comfortable do you feel asking questions with professionals providing therapy?
- How comfortable do you feel participating in your child's treatment?

THE AUTISM SPECTRUM DISORDER CONVERSATION

The importance of continuing the conversations

Ijalba (2016) found that lack of ASD awareness in community adds to mothers' social isolation. Additionally, mothers' felt embarrassment (stigma) related to their child's disruptive social behaviors (e.g., crying, yelling) when attending social functions. In this study, parents understood ASD to be a temporary condition despite their child having a ASD diagnosis for over a year and receiving services in preschool. Parents were also not aware of typical developmental milestones as mothers believed that their child's language would catch up to their peers as they believed that children in their countries often spoke late.

The study completed by Zuckerman et al. (2014) found that parents thought their child's behaviors were in the normal range or they would likely "grow out of" their problems. In this study parents also separated the child's deficits in language, socialization, and behaviors as separate problems and not understanding they were all linked. Due to the lack of awareness of ASD related symptoms and behaviors parents are not adequately informed of the complexity of ASD. Moreover, Ratto, Reznick, and Turner-Brown (2016) found deficits in mothers' knowledge of ASD despite their child being diagnosed 4 years prior of participation on average. This suggests that greater information is provided for Latino communities and further discussions need to occur with the family post feedback session of ASD diagnosis.



DEBUNKING MYTHS

What causes Autism?

As of yet, there is no one identified cause for Autism although there are several theories that discuss genes, the brain, and the environment. It is likely that that ASD is most probably caused by multiple factors interacting in complex ways.

Genetic Factors

Genetics have been shown to have a role in ASD. In Kanner's (1943) initial observations of autistic children observed mild autistic features (e.g. social difficulties and detachment) in their family members. In review of studies have shown that there is a 60-90% probability that an identical twin will develop ASD (Woo & Keatinge, 2016). In a study completed by Ozonoff et al. (2011), investigated the recurrence of ASD in siblings. They found that 18.7% of the identified participants were also diagnosed with ASD. The rates increased if they had an older sibling diagnosed with ASD already and they were male. As Woo and Keating (2016) summarize, the diverse expression of ASD in individuals suggest that there are multiple genes associated with ASD, they can increase the probability of symptoms, and can be impacted by the environment to cause a mutation (e.g. increased parental age).





DEBUNKING MYTHS

The Brain

Studies have found that children with ASD have an increased head size. Courchesene, Carper, and Akshoomoff (2003) found that children with ASD had excessive brain growth placing them in the 85th percentile by 12 to 14 months of age. Additionally, greater and faster rate of brain overgrowth revealed children with more symptom severity when compared to children with milder ASD. Moreover, they found that 90% of children with ASD aged 2 to 4 had a larger than average brain volume (Courchesene et al., 2003).

Environmental Factors

Research in environmental factors causing ASD continue to be sparse. Exposure to air pollution and pesticides are some toxins shown to increase the risk for autism. Additionally, several maternal factors have also shown an increase in ASD which include low vitamin D, prenatal alcohol exposure, deficiencies in prenatal vitamins and folic acid, deficiencies in maternal nutrient reserves. Other factors that increase the risk for autism include high-risk multiple births, gestational diabetes, maternal obesity, infections, and hypertension (Woo & Keatinge, 2016). And finally, the most controversial environmental factor discussed is the impact of the measles-mumps-rubella (MMR) vaccination. Wakefield et al. (1998) found that their participants demonstrated a regression in development and impaired intestinal function leading others to believe that the MMR vaccine was linked to ASD. The study was later retracted for insufficient data to establish a causal link (Murch et al., 2004).

Bilingualism

Latino parents may express concern with their child's delay of language and communication as a result of trying to master two languages (e.g. Spanish and English). Various studies completed do not demonstrate a negative impact for bilingualism in children with ASD. Ohasi et al. (2012) conclude that there are no statistical differences between monolingual and bilingual exposed ASD children. This does not put them in advantage during early stages of language development. Hambly and Fombonne (2012) found no additional language delays in ASD bilingual children when compared monolingual ASD children.

Susto

Susto (sudden fright) is an illness brought on by a frightening experience. In the study completed by Zuckerman et al. (2014) several mothers had concerns that traumatic events, unexplained fear, or their own sadness during the pregnancy were associated to their child's language delays. As of yet, there are no known causes of ASD related to *susto*. Voelkel et al. (2013) found that 46.2 of the Latino parents participating in their study believed that trauma had a significant role in causing ASD.

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DEBUNKING MYTHS

Poor parenting

In the same study completed by Zuckerman et al. (2014) parents without a child with a disability or ASD thought that a child's ASD behaviors were likely due to poor relationships with parents. These parents (without child with a disability) suggested that the ASD child needed "more attention" or "more love" from his parents. This is similar to the previous thought of "refrigerator parents" (Siegel, 1996). It is also possible that for Latino parents, symptoms related to ASD are not recognized as disorders or problems that warrant the help of a professional and instead possibly blame themselves for their inability to control their child's behaviors (Magaña et al., 2013).

In summary, determining the cause of Autism is very complex and still not clear. Although there is some known etiologies there are still many cases with no known cause. This can be both frustrating and possibly comforting to parents. It is frustrating because ASD is very complex and although there are significant advances in research there is still no identifiable cure. However, research conclusions can be possibly comforting to parents as they manage possible feelings of shame or guilt due to a perceived sense of responsibility of their child's diagnosis. Ultimately it is no fault of the parent's action that has lead to their ASD diagnosis. However, parents should be aware that having one child with ASD increases the risk of subsequent children also being diagnosed.

Feelings of shame, guilt, or sense a of responsibility

Parents are likely to experience a wide range of negative feelings in response to their child's initial diagnosis. Specifically, Latino families have endorsed feelings of shame, embarrassment, rejection, guilt and/or a sense of responsibility.

Zuckerman et al. (2014) interviewed parents (without a child with a disability) watched videos and acted as a friend by providing advice to parents with a child demonstrating symptoms and behaviors indicative of ASD. These parents pointed out that problems like ASD might feel somewhat embarrassing or shameful noting that they perceived the Mexican culture to be less accepting or inclusive of a disability. Other shared thoughts included fear of rejection from others, denial due to possible stigma for accepting child's dx, and the fear of telling family members as the problem might cause anxiety (or "nervios") burden on the family. Lajonchere et al. (2016) discovered parents were relieved to find out their child's autism was "not their fault" through their participation of science briefs to understand about ASD. Parents' lack of knowledge on the causes of ASD may lead parents to internalize their child's deficits creating feelings of shame and guilt. Voelkel et al. (2013) found that Latino parents had some understanding of the symptoms associated with ASD, but 60% believed those with ASD would outgrow the disorder and 36.2 knew it was partly a genetic disorder.

A decorative header featuring a dark grey background on the left and a pattern of interlocking puzzle pieces in various shades of grey and black on the right. The puzzle pieces are arranged in a way that they seem to be coming together or falling apart.

DEBUNKING MYTHS

The Future

Some parents may experience grief over their child's future after an ASD diagnosis. However like with any child, parents do not have the ability to see into the future to know their child's potential. Today, a child with ASD has many possibilities for a successful and independent life as they choose. Many adults with Autism hold employment, graduate from college, get married, and have children. Some have created social media platforms on the basis of their diagnosis (www.autisticandunapologetic.com). It is important to help parents understand that their child's future is not impaired by an ASD diagnosis. Steps towards a successful future can start with early intervention with parents actively engaging in their child's treatment to foster their unique strengths

EMPOWERING PARENTS

Coping

Latino parents of a child with ASD are now given the task to cope with the responsibility of understanding their child's diagnosis, navigating a new healthcare system (i.e. occupational therapy, physical therapy, speech therapy, neurologist, geneticist, etc.), navigating a new school system (i.e. Special Education) in a potentially differing language, all while coping with any negative emotional feelings (i.e. shame, guilt) that might be arising. Additionally, everyone in the family will be affected by the new demands. However, depending how the family chooses to cope (i.e. accepting or denying the diagnosis) can determine the road ahead.

Willis et al. (2016) found three broad coping categories are positive coping (problem focused coping such as positive reframing and planning), support coping (emotion focused such as expressing their concerns and seeking instrumental and emotional support from third parties), and avoidant coping (denial and substance use). Those less optimistic were more likely to use avoidant forms of coping, which increased their number of depressive symptoms. In contrast, those who were more optimistic tended to use positive forms of coping that led to a decrease in depressive symptoms. Simply reframing a stressful event (positive reframing) can be an effective coping strategy.

As a service coordinator you will likely build a long lasting working relationship to support and guide the parents with services in the community, become co-advocates for their child in the school system, and also provide emotional support during the yearly visits and conversations throughout the year. It is important to be informative and jargon-free to assist parents learn more about ASD and how to navigate all the new systems. Often, just listening to the parent discuss any frustrations, questions, or concerns they have regarding their child, family, healthcare professionals, and/or service providers can be cathartic. Additionally, this provides an opportunity to problem solve with the family and provide some strategies to help overcome any barriers. Empowerment and advocacy skills in general maybe limited among the Latino families as research shows that Latino families do not feel empowered to meet their children's needs (Magaña et al., 2013).



EMPOWERING PARENTS

Identified barriers in receiving services

As noted above, Latinos make up the largest ethnic groups serviced by WRC, 33%. However, Latinos were one of the highest ethnic groups (17%) not accessing services provided by WRC when compared to other ethnic groups such as whites (12.2%) and Blacks/African Americans (12.8%). Moreover, parents identified some barriers in receiving services that include (Westisderc.org, 2017):

Lack of communication – Parents/Individuals feel

- they do not receive information about services,
- they aren't informed of appropriate services available for their child,
- they are told “no” without receiving their right to appeal,
- that information is hidden.

Lack of Trust/Fear – Parents/Individuals report that

- they are fearful of unknown individuals from an “agency”
- they are afraid for undocumented family members

Potential barriers in actively participating in their child’s treatment planning

While at WRC parents have indicated some possible reasons for the lack in access in services, there are also other possible reasons discovered in research that may inhibit engagement in services.

Language can be a deterrent in someone’s ability to access information if English were his or her second language. Limited English Proficiency (LEP) is the limited ability to understand English as a second language. Often information available to parents is difficult to understand due to lack of information in Spanish. Also, if the information is provided in Spanish the translation is poor or the materials contain language that is difficult to understand (Zuckerman et al., 2014). It is recommended that written materials be accurately translated and at a low reading level.

Moreover, health literacy is receiving information in a way that can be understood (obtained, processed, and understood). Often, medical information uses complex words, specialized vocabulary, and complex scientific and mathematical content. This leaves individuals to decode, interpret, and assimilate health information (Andrulis and Brach, 2007). Having both LEP and limited health literacy increased the likelihood of experiencing confusion and difficulty making sense of relevant health information or information related to their child’s ASD diagnosis (Fernandez et al., 2004). Lajonchere et al. (2016) designed educational information in English and Spanish that provided Hispanic parents of children with ASD access to content published by biomedical research on ASD. Parents wanted to participate in the trainings to learn as much as possible so they could better help their child with ASD. This suggests that parents want to participate and learn when the information is presented in a way that can be readily and easily understood.



EMPOWERING PARENTS

As also noted by WRC families as a concern, immigrant families with undocumented family members in the home experience stress due to the fear of possible detection from authorities and deportation (Dettlaff, 2008). Moreover, this inhibits parents from accessing social services in healthcare and early intervention services for their children (Yoshikawa, 2008). Undocumented family members place parents at real risk for possible deportation and family separation. Additionally, fear of the economic hardship for the remaining family members left to support themselves can also take a further toll on the family. Reduced maternal responsiveness, increased stress, and diminished social supports are factors associated with living in poverty (Evans, Boxhill, & Pinkava, 2008). Culturally responsive parent education and social support systems (e.g., increasing awareness about autism within Hispanic communities) are needed to help caregivers manage their children's behaviors, reduce stress, and improve their wellbeing (Phetrasuwan & Miles, 2009).

Gain skills

As discussed earlier, using the Latino Dimension of Personality Identity Model (Santiago-Rivera et al., 2002) can help guide clinicians when empowering parents with education regarding their child's ASD diagnosis. It also provides a framework for discussing strategies to assist with coping for the possible stressors involved when caring for a child with ASD. For example, a study completed by Valencia-Garcia and colleagues (2012) found that individuals with a higher level of acculturation (e.g. younger age, employed, higher levels of education, higher household incomes) impacted them positively in their perceived ability to access community services, access to social networks, and perceived trust in the community. Additionally, individuals did not endorse symptoms of anxiety or depression when compared to individuals with lower levels of acculturation. Thus parents should be educated about skills and resources to assist in coping with the daily stressors associated with caring for a child with ASD to reduce potential symptoms of depression and anxiety. Moreover, this can be a possible goal to incorporate with families when discussing their child's individualized program plan (IPP).

Build a Strong Social Support Network

Latino parents of children with ASD can find it helpful to talk to other parents of such children. Parents should be encouraged to attend support groups or talk to other parents such as themselves (i.e. at school, occupational therapy, speech therapy, etc.). However, Latino families may struggle with sharing about their child with ASD with others for fear of stigma. Also, parents might believe that their child's diagnosis is a result of God's will (*fatalismo*) and may not see a need to seek out others but instead use their faith as a means to cope.



EMPOWERING PARENTS

Providing parents with education to seek support from other parents can assist them with insightful and invaluable suggestions on how to manage and cope with all the new responsibilities in raising a child with ASD. Moreover, if Latino families are able to support each other and “stick together” (*familismo*), they are more likely to receive recommendations and tips from someone that has experience. Parent to parent support groups are another option to find understanding and support from other families that are also experiencing the same thoughts and feelings. Often other parents can provide guidance and mentorship to families when their child is newly diagnosed with ASD.

La Familia (The family)

A central value to Latinos is *familismo*. Family members can be a significant support system for a family with a newly diagnosed child with ASD. However, some extended family members (e.g. grandparents) may not understand ASD and its implications, therefore they might be reluctant to accept the diagnosis. Extended family members can go through all the same emotional processes that parents do. It can make it difficult for parents if extended family members minimize or disregard their concerns. As information is received from professionals, families should be encouraged to discuss with their family members (*familismo*) so they can come around in accepting the diagnosis and supporting the family. Additionally, extended family members can potentially assist with caregiving duties while the parent attends workshops, support groups, and/ or medical appointments to provide the parent a respite. Extended family members should also be encouraged to participate to also educate and learn new skills.

Self Care

Parents should be encouraged to meet their emotional and physical well-being. This includes adequate nutrition, sleep, and exercise. Clinicians can be met with mixed feelings by parents regarding self-care. Depending on their level of acculturation and strict gender role assignments (*machismo/marianismo*), parents might restrict their openness to engage in self-care. *Machismo* typically refers to the man's responsibility to provide for, protect, and defend his family while *marianismo* refers to mothers as self-sacrificing, selfless, and as pillars of spiritual strength of the family (Santiago-Rivera et al., 2002). As such, a mother's role in a strict gender role assignment family would be to attend to caregiving and domestic duties while the father works and financially provides for the family. Thus, a mother might feel guilty to tend to herself as she might have thoughts and feelings of selfishness when thinking of her own welfare versus the welfare of the family (*familismo*). Some activities that can provide some respite that do not necessarily take time away from the family include: prayer, attending church, bible study, talking a walk, gardening, and listening to music. Most importantly engaging the family with this conversation by exploring ways to find respite in a *familismo* appropriate and meaningful manner.

A decorative header featuring a dark grey background on the left and a pattern of interlocking puzzle pieces in various shades of grey and black on the right. The puzzle pieces are arranged in a grid-like fashion, with some pieces missing or offset, creating a fragmented effect.

EMPOWERING PARENTS

Acknowledgement of Accomplishments

Take a moment and acknowledge all the accomplishments that the parents have achieved. With the challenge of managing a new life with a child diagnosed with Autism, these parents are meeting the demands as they come. The parents have followed through with appointments, met with new professionals, are dealing with a new school system of special education, and they keep going. Parents should be acknowledged for managing these potentially difficult life events. It is validating to a parent by acknowledging, "this is hard and you are doing it" and "you are being the best parent you can be and that is enough." Additionally, by validating a parent's experience demonstrates that you are invested in the wellbeing of the parent and family (*familismo* and *personalismo*).

RESOURCES

100 days Manual

www.autismspeaks.org/family-services/tool-kits/manual-de-los-100-dias

Aprendde: Autismo, educación especial – Monterrey

www.aprendde.com

Autismo Amor

www.autismoamor.com

Autismo Diario

www.autismodiario.org

Autism Society

www.autism-society.org/en-espanol

Autism Speaks

www.autismspeaks.org/about-us/en-espaol

California Autism Professional Training and Information Network

<http://www.captain.ca.gov>

Clima- Clinica Mexicana de Autismo

www.clima.org.mx

Cinter Mexico

www.autismomexico.com.mx

My Child Without Limits (option for Spanish or English)

www.mychildwithoutlimits.org

National Institute of Neurological Disorders and Stroke

www.espanol.ninds.nih.gov/trastornos/autismo.htm

Books

Autismo: Guia Para Padres y Profesionals

Author: Matias Cladaveria and Claudio Waisburg

El Manual de Actividades para el Autismo: Actividades Para Ayudar a los Niños a Comunicarse, Hacer Amigos y Aprender Habilidades Para la Vida

Author: Catherine Pascuas

Cuaderno para Hablar: Programa para facilitar la Comunicación en Niños con Trastornos del Espectro Autista

Author: María José Molero Peinado and Francisca Rivera Leiva

Trastorno del Espectro Autista: Guía Básica para Padres y Educadores

Author: Paul G. Taylor

Support Groups

Parent Empowerment Project (PEP)

Email: pepinfo@autismla.org

Phone: (424) 341-3536

Westside Family Resource and Empowerment Center

Email: Westsidefrec@gmail.com

Phone: (310) 258-4063

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APPENDIX B
PowerPoint Presentation

The Conversation with Latino Parents After ASD Diagnosis

Nancy Guardado, M.A.
Pepperdine University



Objectives

- ◆ Learn how to empower Latino parents when their child is diagnosed with Autism Spectrum Disorder (ASD)
- ◆ Learn about cultural responsiveness when working with Latino families
- ◆ Learn skills to continue the conversation about ASD with Latino families

Disparities

- ◆ What are Disparities?
- ◆ Black and Latino less likely to be diagnosed with ASD versus White children
 - ◆ Are they at a lower risk for ASD?
- ◆ Barriers to Diagnosis
 - ◆ Socioeconomic barriers
 - ◆ Delayed access in evaluation
 - ◆ Delay in diagnosis
 - ◆ Lack of access to healthcare services – non citizenship
 - ◆ Language

Disparities

- ◆ Lack of awareness of ASD symptoms
- ◆ Stigma
- ◆ Healthcare barriers
 - ◆ Dismissing parents concerns
 - ◆ Too difficult to navigate
- ◆ Lack of information in their home country

Disparities

- Two public community meetings with WRC (March 2016)
- Lack of awareness of services that parents not using 100%
- More training to assist parents and families
- No Spanish speaking parents participating in the first meeting

DSM-V : Autism Spectrum Disorder

NUMBER OF CHILDREN IDENTIFIED WITH ASD



1 in 68

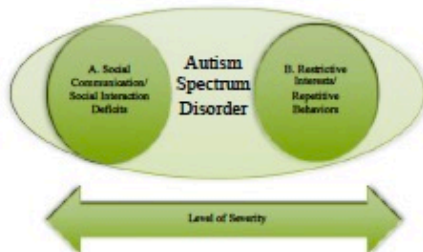


Prevalence of Autism Spectrum Disorder (ASD) in 8-year Olds (2012)

	Overall	About 1 in every "x" children
Sex	Overall	1 in 68
Sex	Boys	1 in 42
	Girls	1 in 189
Race	White	1 in 65
	Black	1 in 76
	Asian/Pacific Islander	1 in 88
	Hispanic	1 in 99

Data courtesy of CDC

Autism Spectrum Disorder



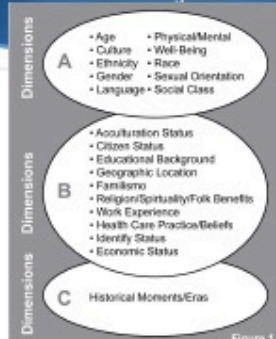
What does it look like?

- No two children will have exactly the same symptoms
- Behaviors can be different with each child
- Severity of symptoms differ
 - Mild to disabling
- Wide range of skills sets with strengths and difficulties
- Symptom severity can change in relation to the support they are accessing
- Stability of diagnosis

Latino in Review

- The term Hispanic: Spanish speaking people
- Latino: People from Latin America
- Share common language, but not all the same
- Different levels of education, migration, histories, acculturation, and socio-economic levels

Latino Dimension of Personality Model



Latinos in Review

- Acculturation
 - Ongoing and dynamic process
 - Adopt and/or merge cultural practice with dominant culture
- Low acculturation perceive more barriers in accessing healthcare services, less exposure to ASD, know someone with ASD
- High acculturation have higher English literacy, communicate better to professionals, access public information

Latinos in Review - Cultural Values

- Familismo
- Personalismo
- Respeto
- Confianza
- Fatalismo
- Platicar

What if it's not Autism?

- ◆ Intellectual disabilities
 - ◆ Deficits in two areas intelligence and adaptive skills
- ◆ Social Communication Disorder
 - ◆ Deficits in social communication
- ◆ Global Developmental Delay
 - ◆ Delays in several areas of intellectual functioning
- ◆ ADHD
 - ◆ Attention, Impulsive, Hyperactivity difficulties

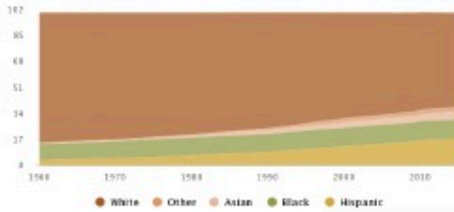
Unique Learning Challenges

- ◆ Attention
- ◆ Social Motivation
- ◆ Use of Gestures
- ◆ Imitation and turn taking
- ◆ Toy play
- ◆ Babble
- ◆ Arousal and Sensory Sensitivities

Latinos in Review

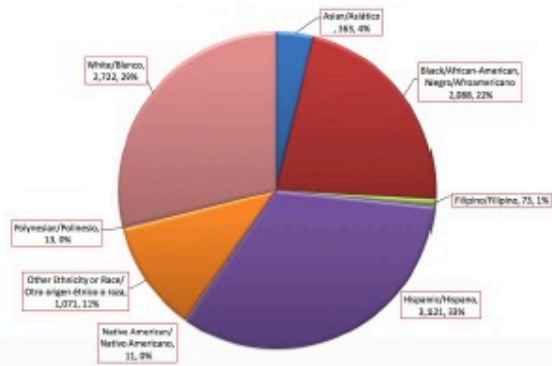
Hispanics are a rising share of the U.S. population

% of total population



PIRG RESEARCH CENTER

Caseload by Ethnicity/Número de Casos por Etnia



The ASD Conversation

- ◆ Feedback
 - ◆ Initial feedback
 - ◆ Investment of hours
 - ◆ Connect process of evaluation and feedback
 - ◆ Starts the process of understand ASD diagnosis
- ◆ Two Key Components of Feedback
 - ◆ Personal connectedness with the family (Familismo)
 - ◆ Openness and honesty (Personalismo)

Continue the Conversation

- ◆ Feedback can be overwhelming
- ◆ Positive and/or negative experience
- ◆ Empower the parent with correct information
- ◆ Questions about ASD
- ◆ Are they adequately informed

Honest Curiosity

- ◆ Questions
 - ◆ When did you first have concerns for your child?
 - ◆ Has your child every received any therapies to help with the concerns expressed?
 - ◆ How was the process of psychological testing?
 - ◆ Did you meet with the psychologist for feedback?
 - ◆ What is your understanding of ASD?
 - ◆ What is your family's understanding of ASD?

Honest Curiosity

- ◆ Questions
 - ◆ Is your family supportive?
 - ◆ Do you feel comfortable telling your family and friends?
 - ◆ How comfortable do you feel asking questions with professionals providing therapy? How comfortable do you feel participating in your child's treatment?

Continue the Conversation

- ◆ Lack of awareness adds to social isolation of mothers
- ◆ Embarrassment, Stigma due to child's disruptive behaviors
- ◆ Child will grow out of symptoms
- ◆ Child will gain language
- ◆ Typical developmental milestones

Causes of ASD

- ◆ No specific cause identified
- ◆ ASD probably caused by multiple factors
 - ◆ Genes
 - ◆ Environment
 - ◆ Brain
- ◆ Still very complex and not clear

Myths

- ◆ Bilingualism: the child is delayed with language because of exposure to multiple languages
- ◆ Susto: sudden fright during the pregnancy or after birth
- ◆ Poor Parenting: Not strict enough or not loving enough; not enough attention

Who's at fault?

- ◆ Parents experience a wide range of negative feelings in response to the child's diagnosis
- ◆ Shame
- ◆ Guilt
- ◆ Sense of Responsibility

Empower Parents

- ◆ Coping with ASD Diagnosis
 - ◆ New healthcare system, professionals, new school system, terminology, possible second language
- ◆ Negative Coping
 - ◆ Denial, avoidant coping styles, and increased depression
- ◆ Positive Coping
 - ◆ Less depression, optimism, reframe and planning

Empower Parents

- ◆ March 2016 Public Meeting WRC Identified Barriers
- ◆ Lack of communication – Parents/Individuals feel...
 - ◆ they do not receive information about services,
 - ◆ they aren't informed of appropriate services available for their child,
 - ◆ they are told "no" without receiving their right to appeal,
 - ◆ that information is hidden.

Empower Parents

- ◆ Lack of Trust/Fear – Parents/Individuals report that...
 - ◆ they are fearful of unknown individuals from an "agency"
 - ◆ they are afraid for undocumented family members

Empower Parents

- ◆ Other Identified Barriers
 - ◆ Limited English Proficiency
 - ◆ Health Literacy
 - ◆ Access to information that is understood
 - ◆ Trust/ Fear
 - ◆ Non-citizenship

Gain Skills

- ◆ Build a Strong Social Support Network
 - ◆ Family
 - ◆ Friends
 - ◆ Support Groups
 - ◆ Other parents at school



Gain skills

- ◆ *La Familia* (The Family)
 - ◆ Education family members
 - ◆ Share information and discuss
 - ◆ Adjustment period for family to grieve
- ◆ Taking Care of Self
 - ◆ Physical Health- walks in the neighborhood
 - ◆ Emotional Health- trusted family or friend share emotional experience

Gain Skills

- ◆ Validate and acknowledge parents
 - ◆ "This is hard and you are doing it"
 - ◆ "You are being the best parent you can be and that is enough"
- ◆ Continue the ASD Conversation
 - ◆ Model and encourage parents to continue educating themselves about ASD

Final thoughts and questions???

Thank you for your time!

Please complete the questionnaire.

APPENDIX C

IRB Approval Letter



Pepperdine University
24255 Pacific Coast Highway
Malibu, CA 90263
TEL: 310-506-4000

NOTICE OF APPROVAL FOR HUMAN RESEARCH

Date: December 06, 2017

Protocol Investigator Name: Nancy Guardado

Protocol #: 15-07-005

Project Title: A Clinician's Training Manual: The Conversation with Latino Parents after ASD Diagnosis

School: Graduate School of Education and Psychology

Dear Nancy Guardado:

Thank you for submitting your application for expedited review to Pepperdine University's Institutional Review Board (IRB). We appreciate the work you have done on your proposal. The IRB has reviewed your submitted IRB application and all ancillary materials. As the nature of the research met the requirements for expedited review under provision Title 45 CFR 46.110 of the federal Protection of Human Subjects Act, the IRB conducted a formal, but expedited, review of your application materials.

Based upon review, your IRB application has been approved. The IRB approval begins today December 06, 2017, and expires on December 05, 2018.

Your final consent form has been stamped by the IRB to indicate the expiration date of study approval. You can only use copies of the consent that have been stamped with the IRB expiration date to obtain consent from your participants.

Your research must be conducted according to the proposal that was submitted to the IRB. If changes to the approved protocol occur, a revised protocol must be reviewed and approved by the IRB before implementation. For any proposed changes in your research protocol, please submit an amendment to the IRB. Please be aware that changes to your protocol may prevent the research from qualifying for expedited review and will require a submission of a new IRB application or other materials to the IRB. If contact with subjects will extend beyond December 05, 2018, a continuing review must be submitted at least one month prior to the expiration date of study approval to avoid a lapse in approval.

A goal of the IRB is to prevent negative occurrences during any research study. However, despite the best intent, unforeseen circumstances or events may arise during the research. If an unexpected situation or adverse event happens during your investigation, please notify the IRB as soon as possible. We will ask for a complete written explanation of the event and your written response. Other actions also may be required depending on the nature of the event. Details regarding the timeframe in which adverse events must be reported to the IRB and documenting the adverse event can be found in the *Pepperdine University Protection of Human Participants in Research: Policies and Procedures Manual* at community.pepperdine.edu/irb.

Please refer to the protocol number denoted above in all communication or correspondence related to your application and this approval. Should you have additional questions or require clarification of the contents of this letter, please contact the IRB Office. On behalf of the IRB, I wish you success in this scholarly pursuit.



Pepperdine University
24255 Pacific Coast Highway
Malibu, CA 90263
TEL: 310-506-4000

Sincerely,

Judy Ho, Ph.D., IRB Chair

cc: Dr. Lee Kats, Vice Provost for Research and Strategic Initiatives

Mr. Brett Leach, Regulatory Affairs Specialist

APPENDIX D

Informed Consent

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

Participant: _____

Principal Investigator: Nancy Guardado, M.A.

Title of Project: Clinician's Training Manual: The Conversation with Latino Parents after ASD Diagnosis

1. I, _____, agree to participate in the research study under the direction of Drs. Carrie Castañeda-Sound, Carolyn Keatinge, and Thomas Kelly.
2. The overall purpose of this research is to create a training manual and presentation to assist clinicians with educating parents about Autism Spectrum Disorder (ASD) in a culturally responsive manner.
3. My participation will involve participating in a presentation and answering a prepared questionnaire.
4. My participation in the study will require approximately 1-2 hours of my time. The study shall be conducted at my convenience.
5. I understand that the possible benefits to myself or society from this research are providing clinicians with a culturally appropriate resource to assist their Latino client's and family with a ASD diagnosis.
6. I understand that there are certain risks and discomforts that might be associated with this research. These risks include the inconvenience of setting aside 1-2 hours of my time.
7. I understand that my estimated expected recovery time after the presentation and feedback questionnaire will be quick.
8. I understand that I may choose not to participate in this research.
9. I understand that my participation is voluntary and that I may refuse to participate and/or withdraw my consent and discontinue participation in the project or activity at any time without penalty or loss of benefits to which I am otherwise entitled.
10. I understand that the investigator(s) will take all reasonable measures to protect the confidentiality of my records and my identity will not be revealed in any publication that may result from this project. The confidentiality of my records will be maintained in accordance with applicable state and federal laws. Under California law, there are exceptions to confidentiality, including suspicion that a child, elder, or dependent adult is being abused, or if an individual discloses an intent to harm him/herself or others.

11. I understand that the investigator is willing to answer any inquiries I may have concerning the research herein described. I understand that I may contact Dr. Castaneda-Sound if I have other questions or concerns about this research. If I have questions about my rights as a research participant, I understand that I can contact Dr. Judy Ho Gavazza, Chairperson of the Pepperdine Graduate Schools IRB), Pepperdine University, at judy.ho@pepperdine.edu or (310) 568-5604.
12. I will be informed of any significant new findings developed during the course of my participation in this research, which may have a bearing on my willingness to continue in the study.
13. I understand that in the event of physical injury resulting from the research procedures in which I am to participate, no form of compensation is available. Medical treatment may be provided at my own expense or at the expense of my health care insurer, which may or may not provide coverage. If I have questions, I should contact my insurer.
14. I understand to my satisfaction the information regarding participation in the research project. All my questions have been answered to my satisfaction. I have received a copy of this informed consent form, which I have read and understand. I hereby consent to participate in the research described above.

Participant's Signature

Witness

Date

Date

I have explained and defined in detail the research procedure in which the subject has consented to participate. Having explained this and answered any questions, I am cosigning this form and accepting this person's consent.

Principal Investigator

Date

APPENDIX E

Post Training Evaluation Form

Training Presentation for Clinicians: The Conversation with Latino

Parents after ASD diagnosis

Post Training Evaluation

A. My Clinical Role at Westside Regional Center (check all that apply)	
<input type="checkbox"/>	Psychologist
<input type="checkbox"/>	Service Coordinator
<input type="checkbox"/>	Other (name)

B. Years of Experience as a Clinician working with children with an ASD diagnosis:	<input type="text"/>
--	----------------------

For each statement below, please circle the response that best characterizes your professional evaluation of the resource manual, where 1= Strongly Disagree, 2=Disagree, 3= Neutral, 4=Agree, and 5=Strongly Agree.

	Weak	Satisfactory	Good	Excellent
1. Topics Addressed:				
a. The presentation covered topics outlined	1	2	3	4
b. The presentation covered the topics with depth	1	2	3	4
c. Order of topics was logical	1	2	3	4
d. The information provided is easy to use	1	2	3	4
2. Ease of the Presentation				
a. The material discussed was succinct	1	2	3	4
b. The speaker was easy to follow	1	2	3	4
3. Format and visual appeal				
a. The graphic design was engaging	1	2	3	4
b. The font was easy to read	1	2	3	4

(continue to next page)

C. Would you encourage your colleagues to attend this presentation in the future to help them facilitate conversations with Latino families? (Please place an X by your response)	
<input type="checkbox"/>	Highly Recommend
<input type="checkbox"/>	Might Recommend
<input type="checkbox"/>	Would Not Recommend

D. Overall was this presentation useful for facilitating conversations with Latino families regarding their child's diagnosis with ASD. (Please place an X by your response)	
<input type="checkbox"/>	Completely Agree
<input type="checkbox"/>	Slightly Agree
<input type="checkbox"/>	Slightly Disagree
<input type="checkbox"/>	Completely Disagree

Open Response

1. Please identify areas in the presentation you would change.

2. Please identify areas in the presentation you would expand and enhance.

3. Any additional comments are greatly appreciated

APPENDIX F
Email Script

Hi, my name is Nancy Guardado and I am a doctoral student in clinical psychology at Pepperdine University. I am in the process of completing my dissertation and have found a need for clinician's when engaging with Latino families newly diagnosed with their child having Autism Spectrum Disorder. The information I have gathered has been compiled into a manual/presentation to be included as regular training for service coordinators and psychologists working for Regional Centers. I am reaching out to you as a potential evaluator of my training, which would include participation in a 90-minute presentation, completion of a short questionnaire of approximately ten questions and providing feedback for improvement before publication. You have been chosen because of your position as a service coordinator or psychologist within the Regional Center and potential expertise in this field. Is this project something that you might be interested in?

If that is a yes... great! As a screening measure for potential evaluators, I have a few questions regarding your background.

- A. Are you a licensed clinical psychologist completing eligibility evaluations for the Regional Center? or Are you a Service Coordinator at Westside Regional Center working with children?
- B. Do you work with Latino families newly diagnosed with ASD?

If you said yes to both questions it appears that you meet all the criteria for inclusion on my panel of evaluators. Would you be willing to participate in my training/presentation and provide feedback regarding areas of improvement?

The training will occur on Thursday, February 15th at 2pm in Room 4E and it be for approximately 90 minutes.

If you have any questions or concerns regarding my study, please do not hesitate to contact me. I can be reached via email nancy.guardado@pepperdine.edu or via telephone at (XXX) XXX-XXXX.

Thank you again for your time and cooperation.

Nancy Guardado, M.A.