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# Toda la Familia: An Occupational Therapy Resource Guide for Working with Latino Children Diagnosed with ASD and Their Families

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Toda la Familia: An Occupational Therapy Resource Guide for Working with Latino  
Children Diagnosed with ASD and Their Families

By

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Submitted to the Occupational Therapy Department

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**Approval Page**

This Scholarly Project Paper, submitted by Rachel Fritzler and Stacey Sigmond in partial fulfillment of the requirement for the Degree of Master of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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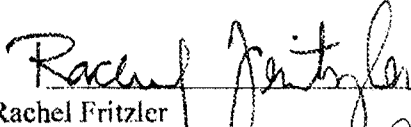
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## ABSTRACT

The purpose of this scholarly project was to create a resource guide for occupational therapists working with Latino children diagnosed with ASD and their families. Autism Spectrum Disorder (ASD) is a developmental disability that has become increasingly prevalent within the United States (Baio, Wiggins, and Christensen, 2018), with ASD rates tripling in Hispanic children between the years of 2002 through 2006 (Pedersen et al., 2002). Blanche, Diaz, Barretto, and Cermak (2015) indicated that multiple family members, not just primary caretakers, are aiding in caring for a child diagnosed with ASD. However, many extended households which may include grandparents, aunts, uncles, and cousins, lack knowledge regarding caring for a child with ASD which can negatively impact child outcomes and family dynamics. This is further becoming a concern as multigenerational households are also increasing (Lofquist, 2012).

In 2011, 10.3 percent, approximately 1.3 million households in the United States were Hispanic extended family households (Lofquist, 2012, p. 5). With an increase in both the extended family caring for the child and multigenerational households, practitioners are confronted with the challenge of holistically treating the family with incorporation of culturally appropriate interventions. However, many practitioners are unaware of how to properly implement family-centered care (Kuo et al., 2011) and research further lacks culturally evidence-based interventions for ASD (DuBay, Watson, & Zhang, 2018).

An extensive review of literature was completed on ASD, ASD in Latino children, family-centered care, family networks, culturally appropriate interventions for

ASD, and the role of occupational therapy in working with ASD to develop a resource guide that would aid the occupational therapy process. The developers utilized reliable databases, textbooks, and the American Occupational Therapy Association to obtain information. Based on the findings and gap in literature, the developers selected the Family Systems Theory and the Ecology of Human Performance to develop the culturally adapted family-centered based resource guide for occupational therapists working with Latino children diagnosed with ASD and their families.



## **CHAPTER 1**

### **Introduction**

Autism Spectrum Disorder (ASD) is a neurological condition that has become increasingly prevalent within the United States. According to Baio, Wiggins, and Christensen (2018), “1 in every 59” children are diagnosed with ASD (p. 9). ASD is characterized by difficulties with communication, strained social interactions, restricted interests and repetitive behaviors (American Psychiatric Association [APA], 2013). Literature indicates that ASD prevalence in Hispanic children has increased in recent years, almost tripling from 2000 to 2006 (Pedersen et al., 2012). Latino children diagnosed with ASD often present with more severe symptoms compared to non-Latino children diagnosed with ASD and are diagnosed later in life (Liptak et al., 2008; Zuckerman et al., 2014b). With an increase in Latino children diagnosed with ASD and presenting with more severe symptoms, another factor that occupational therapists must consider is implementing culturally appropriate evidence-based interventions.

Though there is this rising area of concern to provide culturally appropriate evidence-based interventions, a majority of the literature review identified that research on ASD interventions is completed with White, mid to upper-class children rather than ethnic minorities (Dubay, Watson, & Zhang, 2018). This reduces an occupational therapist’s ability to provide culturally appropriate evidence-based intervention and provide holistic care to Latino children diagnosed with ASD and their families. Furthermore, incorporating family into interventions is increasing (Blanche, Diaz,

Barretto, & Cermak, 2015), however, there are misunderstandings on how to provide family-centered care in the healthcare system (Hodgetts Nicholas, Zwaigenbaum, & McConnell; Kuo et al., 2012; Mackean, Thurston, & Scott, 2005).

The purpose of this scholarly project was to address misunderstandings in family centered care (FCC), culturally appropriate services, and the gap of literature concerning Latino children diagnosed with ASD and their families. The product titled, *Toda la Familia: An Occupational Therapy Resource Guide for Working with Latino Children Diagnosed with ASD and Their Families*, was a resource guide developed to aid occupational therapists in increasing knowledge on Latino culture, providing services that incorporate culture, and decreasing bias when working with this ethnic minority group. A critical component of the resource guide was the integration of family and was the foundation for the authors selecting Family Systems Theory (FST) and Ecology of Human Performance (EHP) as the theoretical frameworks for this project.

FST is a theory that allows an occupational therapist to comprehend family dynamics and assist with incorporating family into the therapeutic process. Kerr (2000) states that FST is a “theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit. It is the nature of a family that its members are intensely connected emotionally” (p. 1). This theory will aid occupational therapists in understanding a family as a whole entity and will provide the therapist with comprehension about a family’s communication style, relationships and contextual influence on their family dynamics (Dykeman, 2016). Walsh (2009) reports that FST is applicable to the Latino population and that therapists will need to consider family solidarity, religion/spirituality, and cultural roles within the Latino family when

applying FST. A therapist will be able to identify these components by understanding FST's eight primary principles: triangles, differentiation of self, nuclear family emotional process, family projection process, multigenerational transmission process, emotional cutoff, sibling position, and society emotional process (Dykeman, 2016; Kerr, 2000; Walsh, 2009). These eight principles are included in the product with definitions and simulated examples to provide occupational therapists with illustrations on how the principles and/or family dynamics may appear in the clinic with a Latino family. FST is a psychology-based theory and was paired with EHP to provide an occupational therapy perspective, as well as aid in the occupational therapy therapeutic and intervention process.

According to Turpin and Iwama (2011), a key feature of EHP is the significance of the context and environment. According to Dunn, Brown, and McGuigan (1994) environments such as physical, temporal, social, and cultural factors impact behavior of the child. Research on Latino culture has recognized the importance of the familial context, specifically the extended-family environment as an integral cultural component in the Latino population (Hardwood, Leyendecker, Carlson, Asencio, & Miller, 2002). Through the lens of EHP, the practitioner is able to integrate the family into the therapeutic process due to its emphasis on context and how context impacts behaviors. When using EHP to guide the therapeutic process, the concept of the environment shapes how people view themselves and what they do. According to (Dunn, 2017), one cannot understand the person without first understanding the context. Additionally, occupational therapists are equipped with the skills to understand the interdependent relationship between the person and the context (Turpin & Iwama, 2011). This theory allows for the

therapist to integrate the family's wants and needs into the intervention planning and implementation. Latino families are well-known for being inclusive and typically surround themselves with their extended family for support.

Following the introduction, chapter II is a literature review that examines the prevalence of ASD, ASD in Latino children, lack of culturally appropriate interventions addressing minority ethnic groups, misunderstandings of FCC, family networks, psychosocial components related with multiple members involved in child rearing, barriers to care, the role of occupational therapy in ASD, and the theoretical foundation of FST and EHP. Chapter III is a methodology report that provides information on how the authors obtained their information and the process they underwent in creating their product. Chapter IV is the product in its entirety. The product includes nine sections/headers with pertinent information and incorporation of FST and EHP to aid an occupational therapist in the therapeutic and intervention process. Lastly, chapter V is a summary of the scholarly project. This chapter provides a brief summary of each section and further provides recommendations and limitations to consider for future research.

Key terms operationally defined and utilized in the project are presented below:

*Autism Spectrum Disorder (ASD):* A neurodevelopmental disorder marked by deficits in social interaction and communication across several contexts; is characterized by impairments in social-emotional exchange, non-verbal communication, and development of relationships (APA, 2013).

*Culture:* Attitudes, values, and beliefs shared by a group of people that influences behaviors (Mandell & Novak, 2005).

*Latino:* "A native or inhabitant of Latin America" (Morris, 1985, p. 717).

*Hispanic*: “Pertaining to the language, people, and culture of Spain, Portugal, or Latin America” (Morris, 1985, p. 613).

*Familismo*: Loyalty to the family that is associated with a strong sense of responsibility, dedication, and obligation to family members. (Bernal, Morales-Cruz, & Gomez Arroyo, 2016)

*Interdependence*: “Generally, a pattern of action and thought that focuses on the relationships between self and other(s) and emphasizes the importance of positive interpersonal behaviours such as cooperation” (Interdependence, 2009, para 1).

*Extended Family*: “A family unit making up one household that consists of parents, children, and other close relatives, such as grandparents or aunts” (Morris, 1985, p. 479).

*Nuclear Family*: “A self-contained family unit consisting of a mother and father and their children” (Morris, 1985, p. 851).

*Multigenerational Household*: Households that consist of three or more generations residing together (Lofquist, 2012).

*Family-Centered Care*: An approach to decision making between the healthcare professional and family (Kuo et al. 201

## **CHAPTER 2**

### **Literature Review**

#### **Introduction**

Autism Spectrum Disorder (ASD) is a developmental disability that has become increasingly prevalent within the United States. As previously identified, children diagnosed with ASD has risen to 1 in every 59 children (Baio et al., 2018, pg. 9). With the increase in children diagnosed with ASD, it has also been found that multiple family members are becoming increasingly involved in caring for a child diagnosed with ASD (Blanche, Diaz, Barretto, & Cermak, 2015). According to Ekas et al. (2016), social supports such as family are shown to increase positive outcomes. For example, grandparents can aid parents through financial support, respite care, and providing emotional support (Hillman, Wentzel, & Anderson, 2017). Families living with and raising a child diagnosed with ASD experience more challenges compared to families with typically developing children (Blanche et al., 2015; Giallo, Wood, Jellett, & Porter, 2011; Goepfert, Mulé, Von Hahn, & Siegel, 2015; Hsiao, 2018). Families raising a child with ASD in a multigenerational household are likely to experience a decrease in health and well-being, increase in social isolation, and under-utilization of healthcare services (Harrigan, 1992; Hillman et al., 2017; Riley & Bowen, 2005; Willis et al., 2016). For families living in a multigenerational household, these challenges can be intensified due to the addition of psychosocial factors associated with living in a multigenerational

household. In 2011, 10.3 percent, or approximately 1.3 million households in the United States were Latino extended family households (Lofquist, 2012, p. 5).

A large body of research has been completed regarding ASD, however, there is limited research regarding multigenerational households. Additionally, little research has been conducted regarding extended family members such as grandparents, aunts, uncles, or cousins in the context of having a child diagnosed with ASD in the family.

Furthermore, there is insufficient research regarding social and cultural influences on families' experience with a child diagnosed with ASD, specifically in the Latino culture. With the increasing prevalence of ASD, a growing Latino population, and the steady rise of multigenerational homes and extended family support, this is a topic that must be researched.

### **Autism Spectrum Disorder**

ASD is a neurodevelopmental disorder marked by deficits in social interaction and communication across several contexts and is characterized by impairments in social-emotional exchange, non-verbal communication, and development of relationships (APA, 2013.) According to the APA (2013), in addition to social interaction and communication deficits, a child diagnosed with ASD may present with repetitive and restricted behavior patterns. For example, repetitive and stereotyped motor movement, speech, or use of objects is common including, the act of lining up toys, echolalia, and flipping objects. The child may also be inflexible with routines and demonstrate ritualized patterns of behavior including eating the same food every day, extreme distress when small changes in routine occur, and difficulty with transitions. It is not uncommon that the child will have restricted interests and preoccupation with unusual objects. The child may also

demonstrate hypo- or hyperactivity to sensory stimuli including being impervious to temperature/pain, extreme touching or smelling of objects, and fascination with movement or lights (APA, 2013).

According to the APA (2013), the severity of the disorder has the ability to alter over time and vary by environment. Different levels of ASD are described by the Diagnostic and Statistical Manual (2013) including Level 1 “Requiring support”, Level 2 “Requiring substantial support”, and Level 3 “Requiring very substantial support” (APA, 2013, p 52). Children falling into the severity rating of “requiring support” (APA, 2013, p. 52) or Level 1 are capable of speaking in full sentences and engaging in communication, however, often have difficulty initiating, maintaining, and terminating conversation successfully. Additionally, the child may display limited interest in social interaction and demonstrate unsuccessful attempts at initiating social interaction, without supports in place. Inflexible behaviors are often present, especially when shifting from one activity to another (APA, 2013).

Children specified as “requiring substantial support” (APA, 2013, p. 52) or Level 2 have distinct deficits in social interaction even with social supports in place. Deficits include both limited initiation of interaction in social settings and diminished or atypical responses during engagement with others. This can be traced to limited interests, deficits in nonverbal communication, and speaking in simple sentences. Additionally, the child will demonstrate restricted and repetitive behaviors, difficulty coping with change which impacts functioning in various contexts (APA, 2013).

Finally, children specified as “requiring very substantial support” (APA, 2013, p. 52) or Level 3 have severe deficits in social communication skills including verbal and



nonverbal language. Social interaction is limited, and the child will display minimal response during interpersonal engagement others. Extreme difficulty coping with change is evident as well as inflexible behaviors that greatly interfere with functioning causing distress during change (APA, 2013).

### **Prevalence**

ASD impacts individuals across the lifespan and is continuously increasing throughout the United States (Baio et al., 2018). Kogan et al. (2009) identified that possible contributions to the prevalence of ASD included increased awareness in the general population, refined screening tools, and comprehensive questionnaires for parents and primary care providers. The rise in ASD is impacting multiple ethnicities. Pedersen et al. (2012) identified that although non-Hispanic White children were more commonly diagnosed with ASD, the Hispanic rate of ASD in children increased approximately five percent between 2000-2006. Baio et al. (2014) reported that Latino children with ASD increased by “110%” during 2002 through 2008 (pg. 14). Although the Hispanic and Latino rate of ASD in children has increased, Mandell et al. (2009) reported that Hispanic children are still continuously diagnosed later in life compared to non-Hispanic White children. This is important for healthcare professional and families to understand as Hispanic children with ASD tend to present with more severe symptoms (Liptak et al., 2008; Zuckerman et al., 2014b), which will influence the treatment process.

The continuous rise in ASD is also impacting multiple households including multigenerational homes, which are multiplying in the U.S. Multigenerational households are defined as family households where three or more generations are residing (Lofquist, 2012). Interestingly, multigenerational households are increasing as a result of racial and

ethnic diversity, education levels, immigration, and housing affordability (Cohn & Passel, 2018). In 2011, 10.3 percent, approximately 1.3 million households in the United States were Hispanic extended family households (Lofquist, 2012, p. 5). With Hispanic households representing a majority of the multigenerational households identified in the United States and Latinos being one of the fastest growing ethnic groups (Flores, 2017), it is expected that a Hispanic child diagnosed with ASD may live in a multigenerational household and that extended family will be involved during the treatment process.

With this emerging cultural trend, clinicians will need to provide holistic care to Latino children diagnosed with ASD and their families. It is imperative that health care providers understand the Latino culture, family dynamics, including extended family, and the cultural perception of ASD and how it may influence the trajectory of treatment.

### **Extended Family, Multigenerational Households, & Psychosocial Factors**

Family is a fundamental aspect of society and lays the framework for societal norms and trends. The U.S. Census Bureau (2015) described the family as a group of two or more people related to one another through birth, adoption, or marriage and who are residing together. Within the United States, the concept of family is often related to the nuclear family, which includes a mother, father, and child (University of Notre Dame Institute for Latino Studies, 2009). However, it is typical that Latino families live with or live in close vicinity to extended family members (Soto-Fulp & DelCampo, 1994). Pew Research Center (2010) reported that multigenerational homes are more commonly found throughout ethnic families and continue to be a societal trend in the United States.

Extended family is described as family members outside of the nuclear family. This can include, but not limited to, grandparents, aunts, uncles, and cousins, and can vary from

family to family (Morris, 1985; Soto-Fulp & DelCampo, 1994). It is widely accepted and normal for Latino families to arrange themselves around an extended family network (Soto-Fulp & DelCampo, 1994). These types of households are described as three or more generations residing within a home including the homeowner, grandparents, and grandchildren (Kim, Spangler, & Gutter, 2016). For the purpose of this literature review, when using the term *multigenerational* it is the expectation that the extended family is residing within the home. When discussing the topic of extended family or a multigenerational household these terms are correlated to one another within the family network and are interchangeable.

The Latino population represents approximately “27%” of multigenerational households in the U.S. and is expected to rise (Cohen & Passel, 2018, para. 5). As this trend continues to increase, it is crucial that healthcare professionals examine family dynamics within the home, outside the home, and how interactions between family members can impact quality of life. Living in a multigenerational home can contribute to both positive and negative familial interactions that influence family dynamics.

Barnett, Mills-Koonce, Gustafsson, and Cox (2012) reported that the complexity of understanding familial roles increases when collaboration between family members is utilized to raise a child within the same home. Hillman et al. (2017) identified that many grandparents are unfamiliar with their role as grandparents once their grandchild becomes diagnosed with ASD. Grandparents also find difficulty in supporting their child without undermining their child’s parental role (Margetts, Couteur, & Croom, 2006). Grandparents may not be the only family members facing a disruption in roles and it is imperative for occupational therapists to examine role changes, role demands, and role

conflict within the family context. Furthermore, it is imperative that healthcare professionals examine the psychosocial factors of extended family members and individuals residing in a multigenerational home, as psychosocial factors within these contexts influence the quality of life and family dynamics.

There are identified advantages of psychosocial factors correlated with living in a multigenerational household, including increased resources, closeness, support, and stability (Easthope, Liu, Burnley, & Judd, 2017; Harrigan 1992). Despite the positive effects of extended family support within a multigenerational home, literature has also identified negative psychosocial factors such as symptoms of depression, anxiety, increased conflict, house stress, child-care stress, and privacy issues (Harrigan 1992; Riley & Bowen, 2005). Furthermore, research suggests that families living in a multigenerational home experienced intra-family strain and increased stress as a result of living within this type of household (Musil, Jeanblanc, Burant, Zauszniewski, & Warner, 2013). Intra-family strain can lead to changed family dynamics, communication difficulties, and an overall decrease in well-being (Musil et al., 2013). After an examination of the literature, minimal research was found on extended family experiences and psychosocial factors when interacting with a child family member diagnosed with ASD.

Soto-Fulp and DelCampo (1994) identified that an extended family has proven to be functional for several generations, however, it has the potential to create additional stress for the family. Research has emphasized experiences related to parent, caregiver, and grandparent interactions with a child in the family diagnosed with ASD rather than the extended family experience. In a research study conducted by Lopez, Yue, Magana,

and Guzman (2018), it was identified that Latina mothers experienced unique reactions from multiple family members about their child diagnosed with ASD. For example, Latina mothers identified that some family members thought that the ASD diagnosis was something she (the mother) did with regard to raising her child. Furthermore, some family members thought ASD could be cured, others thought a natural healer could assist, and some believed the child was simply spoiled. Lopez et al. (2018), further identified that stigma negatively influenced extended family support for both White mothers and Latina mothers. When providing family-centered care it will be critical that a healthcare professional examine both positive and negative psychosocial factors to increase familial cohesion and provide a positive environment for a child diagnosed with ASD and caregiver support.

Understanding perspectives of immediate family members and grandparents can provide occupational therapists insight on some of the common psychological symptoms that family members experience when living in a multigenerational home or caregiving for a child with ASD. Hillman et al. (2017) reported that grandparents experienced challenges and stressors when caring for a child diagnosed with ASD, but still reported satisfaction when experiencing unique interactions with their grandchild. Hispanic mothers compared to Hispanic fathers reported higher use of positive coping strategies, and greater support, but also a higher report of depressive symptoms (Willis et al., 2016). Lopez et al. (2018) identified that Latina mothers reported a heightened sense of guilt once learning of their child's diagnosis compared to the response of White mothers. White mothers identified that the diagnosis of ASD brought them a sense of relief. Furthermore, only Latina mothers in this study identified injustice about their child's

diagnosis (Lopez, Yue, Magana, & Guzman, 2018).

With an increase in both the extended family caring for the child and multigenerational households, practitioners are faced with a new challenge; the challenge is the need to treat whole families, rather than the just nuclear family. However, many practitioners are unaware of how to properly implement family-centered care (Kuo et al., 2012).

### **Hispanic ASD**

There is disagreement among researchers regarding prevalence rates among different ethnic and racial minorities. A number of researchers argue that the prevalence rates of ASD do not change (Tek & Landa, 2012; Zuckerman et al., 2014a), while others argue that prevalence rates are lower in Hispanics, African Americans, and Asians (Ijalba, 2016; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Ratto, Reznick, & Turner-Brown, 2016;). Although there is disagreement regarding prevalence among researchers, one fact that is agreed upon is a delay of diagnosis in minority populations. Unlike Caucasian children, children of ethnic groups are less likely to receive an early diagnosis of ASD (Tek & Landa, 2012; Zuckerman et al., 2014a). This may be attributed to cultural differences and socioeconomic barriers including stigma attached to the diagnosis, high-poverty rates in densely populated areas, restricted access to care, and language barriers (Voelkel, LeCroy, Williams, & Holschuh, 2013). Culture is characterized as a set of patterns, beliefs, and attitudes shared by a group of people that influences their way of life (Mandell & Novak, 2005; Ravindran & Meyers, 2011). Often, these beliefs and behaviors are passed from generation to generation and embedded into the family dynamic (Mandell & Novak, 2005). Cultural values and traditions impact the meaning

parents associate to their children's symptoms and the etiology of the condition. Additionally, what the American culture depicts as the standard of early indicators of ASD, may not evoke concerns at an early age in minority cultures. Therefore, different beliefs and cultural practices regarding child development impact early detection and services (Tek & Landa, 2012). According to Lobar (2014), behaviors typically associated with ASD are seen in early stages of life as socially constructed and differ within the family unit and cultural environment. For example, according to Patcher and Dworkin (1997), compared to Caucasian mothers, Puerto Rican mothers often expect social milestones at later stages for their children, such as recognizing the mother and smiling at faces.

### **Hispanic Culture**

Research specific to the Latino culture has uncovered important traditional values such as *familismo* and *fatalismo* (Hartmann et al., 2018; Mandell & Novak, 2005). *Familismo* is the concept of loyalty among the nuclear and extended family (Hartmann et al., 2018). This concept can be related to a collectivistic perspective which influences family interactions. Latino families value collectivism while Westernized cultures typically value an individualistic perspective (Patcher & Dworkin, 1997; Turpin & Iwama, 2011). The value of collectivism stresses the importance of the welfare of the group, extended family, and interdependence among group members (Patcher & Dworkin, 1997). Collectivism is demonstrated through the distribution of family roles, child-care responsibilities, and the importance of family matters (Patcher & Dworkin, 1997). Additionally, Latino families typically described the family as mutual support among one another (University of Notre Dame Institute for Latino Studies, 2009).

According to Bernal, Morales-Cruz, and Gomez-Arroyo (2016), extended family assures mutual caretaking and protection. Extended family networks are often affiliated with the feelings of cohesiveness and a sense of belonging (Soto-Fulp & DelCampo, 1994).

*Fatalismo* is the belief that what occurs in life is fate and that one cannot change the trajectory of their destiny, which could detour parents from seeking medical care (Mandell & Novak, 2005). These traditional values impact health behaviors, treatment decisions, and intervention implementation. Specifically, *familismo* has the ability to impact family interactions and decision-making. According to Blanche et al. (2015), a common theme among extended family members was that they would adopt a wait-and-see attitude in regard to the child's developmental delays. Many of the family members resisted the diagnosis, attributing the symptoms to life phases or blaming it on poor parenting. Additionally, family members would provide inaccurate knowledge and voice opinions rather than accepting the diagnosis. Blanche et al. (2015) also reported that parents described their experiences in relation to extended family and the hardships they endured. Many of the parents felt that the extended family had a more difficult time understanding and accepting the diagnosis of ASD (Blanche et al., 2015).

Stigma and isolation may be contributing factors to late diagnosis of ASD in the Latino population. Literature has suggested that embarrassment, shame, and fear of familial rejection are often associated with disability in general, but even more so with mental health problems (Blanche et al., 2015; Lobar, 2014; Zuckerman et al., 2014a; Zuckerman et al., 2014b). The stigma attached to the condition often prevents parents from seeking medical treatment leading to isolation from their community (Blanche et al., 2015; Zuckerman et al., 2014a). For example, Blanche et al. (2015) explained that parents



involved in a focus group designed to help researchers understand experiences of Latino families raising a child diagnosed with ASD reported they would refrain from telling others about their child's diagnosis in order to avoid hearsay. Parents also reported that they felt angry their child was singled out within the community due to their diagnosis. For example, the child was referred to as different or special, labels the parents and siblings felt ashamed of (Blanche et al., 2015; Divan, Vajaratkar, Dessai, Strik-Lievers, & Patel, 2012). Divan, Vajaratkar, Dessai, Strik-Lievers, and Patel (2012) reported that community intolerance was present and that community members often made negative comments. In addition to social isolation, parents will try to conceal atypical behaviors so that people in the community cannot judge them (Blanche et al., 2015; Zuckerman et al., 2014b). One mother reported she would tickle her child when he would laugh for no apparent reason to cover up the child's atypical behavior (Blanche et al., 2015.)

### **Barriers to Care**

Latino parents and extended family of a child with ASD report the diagnosis in itself to be challenging due to lack of knowledge, the importance of cultural values, and the stigma attached to a diagnosis of ASD. Furthermore, they are left to navigate the healthcare system with little guidance while attempting to overcome other obstacles to care such as language barriers, limited ASD knowledge, and low socioeconomic status (SES) (Zuckerman et al., 2014a; Zuckerman et al., 2014b). A parent's knowledge of ASD influences age of diagnosis, discrepancies in severity, and use of services (Magaña, Lopez, Aguinaga, & Morton, 2013). Many Latino parents had reported limited knowledge regarding ASD. Some even admitted they had never heard of the diagnosis. For parents who had heard the term ASD, few could describe what the condition was and

associated it with a negative connotation (Zuckerman et al., 2014a; Zuckerman et al., 2014b). Parents of children diagnosed with ASD reported that they sought information through the internet, neighbors, local organizations, and family members (Blanche et al., 2015). When parents were provided with information by a healthcare provider, they were given pamphlets or limited information regarding the next steps in care (Blanche et al., 2015). Literature suggested that healthcare professionals do not supply appropriate support and generally have low awareness for the unique needs of Latino families with a child with ASD (Blanche et al., 2015; Derguy, Michel, M'Bailara, Roux & Bouvard, 2015; Divan et al., 2012).

Another challenge faced by Latino extended families with a child with ASD is the language barrier. According to Voelkel et al. (2013), the inability to communicate with healthcare professionals is a key contributor to parents not seeking medical services. Parents have reported that the inability to communicate with their healthcare provider resulted in miscommunication and adverse health outcomes (Voelkel et al., 2013). Blanche et al. (2015) reported that the need for early intervention and services were not emphasized to parents. Parents attributed this misinformation to the language barrier. Additionally, Latino parents reported that informational material was poor quality and often the Spanish translation was incorrect (Zuckerman et al., 2014a).

Literature has suggested that an important factor to consider in Latino populations is the impact of SES (Colbert, Webber, & Graham., 2017; Voelkel et al., 2013; Zuckerman et al., 2014a; Zuckerman et al., 2014b). Zuckerman et al. (2014b) reported that poverty affects access to care as a result of a lack of money for transportation or child care or restricted insurance coverage. Families living in high poverty neighborhoods

have been reported to have difficulty accessing care due to financial restraints within the community. Voelkel et al. (2013) reported that high-poverty communities are rarely prepared to meet the needs of children diagnosed with ASD. This can be contributed to the school's inability to hire professionals proficient in evaluating students. Additionally, hospitals in the poor sectors are typically unable to hire the full provision of healthcare staff to support the demands of the surrounding population (Voelkel et al., 2013). For example, the hospital may not be able to hire bilingual healthcare professionals or interpreters. This gap in the provision of care then relates back to findings that indicate Hispanic families have difficulty accessing service due to the inability to communicate with the healthcare professionals (Voelkel et al., 2013).

### **Family-Centered Care**

Many families with a child diagnosed ASD have reported that they had difficulty accessing care and were unsatisfied with care provided (Blanche et al., 2015; Divan et al., 2012). Blanche et al. (2015) reported that parents received written information pertaining to their child's diagnosis, yet service providers did not emphasize the need for service. In a qualitative study conducted by Mackean et al. (2005), parents reported that they felt the healthcare professionals provided the diagnosis in a reasonable manner but then expected the parents to find appropriate services for their child. Additionally, research suggested that healthcare providers are unaware of the special needs of families with a child with ASD, especially when providing culturally competent care (Blanche et al., 2015; Derguy et al., 2015; Divan et al., 2012; Voelkel et al., 2013). Combining this problem with the increase of multigenerational households translates to a gap in healthcare provision.

Utilizing a family-centered approach, healthcare providers would be able to better

serve this population. Kuo et al. (2012) described family-centered care (FCC) as an approach to decision making in the healthcare context. The American Academy of Pediatrics Committee on Hospital Care (2003) indicated that when FCC is adopted in a healthcare facility, practitioners are then able to recognize the crucial role families play in the well-being of the child being treated. Additionally, when FCC is applied to practice, research indicated that there is an increase in child outcomes and in parent satisfaction (Hodgetts et al., 2013).

While FCC is an essential component to treatment, there are misunderstandings on how to implement FCC principles (Kuo et al., 2012). Specific to ASD, challenges in providing FCC is correlated to settings in which intervention is typically provided to a child with ASD. For example, intervention is generally provided to children in the school setting, which is unlikely to implement FCC (Hodgetts et al., 2013). Another misunderstanding in the utilization of FCC is the assumption of responsibility that the healthcare provider places on parents. According to Mackean et al. (2005), the healthcare professionals reported they viewed their role as more of consultant where they provided the information and occasional support. However, parents reported that they would have preferred to collaborate with the healthcare professional to design and implement a care plan to meet their child's needs (Mackean et al., 2005). Finally, in a study conducted by Hodgetts et al. (2013), parents reported there was a lack of transparency and continuity of care as their child aged. Parents described their experiences as “having to pull teeth” or “a full-time job” when trying to access services for their child once they got older (Hodgetts et al., 2013, p. 142).

### **Role of Occupational Therapy**

Children with a diagnosis of ASD experience an extensive variety of difficulties including inflexibility, adherence to familiar routines, limited social skills, restricted interests, repetitive behavior, and hypo- or hyperactivity to sensory experiences (APA, 2013). These difficulties lead to impairments in everyday roles, routines, and habits that impact overall occupational performance. Occupational therapy is an already a recognized member of the interdisciplinary team and often focuses on sensory or motor skills (Kuhaneck & Watling, 2015). However, if their role in treatment could be expanded into focusing on family health and well-being overall, outcomes would be enhanced. Occupational therapy practitioners are equipped with the skills and knowledge to collaborate with families in order to decrease stress, depression, and anxiety related to the difficulties encountered when raising a child with ASD.

Occupational therapists are equipped with the skills necessary to provide FCC for multigenerational households to increase the overall well-being of the family members and provide culturally competent intervention to the child. Occupational therapy is a holistic profession that aims to include both the patient and their family in the development of the treatment plan and the decision-making process. According to Neuhaus (2000), there are several strategies that occupational therapy practitioners are familiar with for the implementation of FCC for multigenerational households to utilize. The first strategy is to utilize the knowledge of the correlation between life stages and the transitions between them. This includes being culturally aware of age, gender, disability, religion, ethnicity and the autonomy of an individual. A second strategy focuses on each family member having an active role in the therapy process. The third and final strategy includes decreasing tension between family members by educating families on social

supports available.

### **Theoretical Foundation**

Individuals are typically influenced by their surroundings, including their family. When understanding an individual, one must first understand the individual's beliefs and values, which typically stems from one's familial or cultural background. This can pose as a challenge as families are dynamic and ever-changing. Kerr (2000) states that the Family Systems Theory is a "theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit. It is the nature of a family that its members are intensely connected emotionally" (p. 1). By understanding a family as a whole entity, health care professionals can gather information about communication styles, relationships, and contextual influences on family dynamics (Dykeman, 2016).

The Family Systems Theory is applicable to a variety of cultures. Walsh (2009) reported that when applying the Family Systems Theory to the Latino population, a health care professional must consider the importance of family solidarity, religion/spirituality, and cultural roles within the family. This theory will provide the student researchers the foundation to understand the complexity of extended family and familial interaction within a Latino home. By increasing knowledge on family dynamics, the healthcare professional will be able to implement holistic family-centered to the family.

The Family Systems Theory will be used in conjunction with the occupational-based theory Ecology of Human Performance (EHP). The second theory was chosen to supplement the Family Systems Theory and provide the addition of an occupational

therapy perspective. According to Turpin and Iwama (2011), a key feature of this theory is the significance of the context and environment. Research on the Latino culture has recognized the importance of the family context, specifically extended-family as an integral cultural component in the Latino population (Hardwood et al., 2002). Through the lens of EHP, the practitioner is able to integrate the family into the therapeutic process due to its emphasis on context and how context impacts behaviors. When using EHP to guide the therapeutic process, the concept of the environment shapes how people view themselves and what they do. According to Dunn (2017), one cannot understand the person without first understanding the context. Additionally, occupational therapists are equipped with the skills to understand the interdependent relationship between the person and the context (Turpin & Iwama, 2011). This theory allows for the therapist to integrate the family's wants and needs into the intervention planning and implementation. Latino families are well-known for being inclusive and typically relying on extended family for support. Therefore, by applying EHP, the OT is then able to consider the extended familial context and how it influences the family's wants and needs for their child.

## **Conclusion**

After a review of the literature, it is evident that there are multiple cultural components that can influence a family's decision in selecting a treatment process for their child diagnosed with ASD. According to Blanche et al. (2015), many families refer to their cultural background as central to their daily life. Furthermore, parents reported that their culture influenced how they experienced ASD (Blanche et al., 2015). Parents raising a child with ASD experience a decrease in overall health and well-being (Blanche et al., 2015; Divan et al., 2012; Hsiao, 2018) Additionally, when extended family is

involved relationships become strained, there is a disruption of roles and a decrease in family cohesion (Margetts et al., 2006; Musil et al., 2013). While the support of the extended family does have benefits, it is important to recognize the complex psychosocial aspects correlated with extended family support.

Literature suggests the healthcare system is not prepared to meet the demands and the increase in children diagnosed with ASD. Furthermore, that unpreparedness is increased when culture is taken into consideration (Mandell & Novak, 2005). Family Systems Theory and the EHP model will provide the foundation for the student researchers in developing a resource manual for occupational therapists to utilize when providing family-centered therapy to Latino families with children diagnosed with ASD.



## CHAPTER III

### Methodology

The purpose of this scholarly project was to aid occupational therapists in providing culturally appropriate services to Latino children diagnosed with ASD. Our product titled, *Toda la Familia: An Occupational Therapy Resource Guide for Working with Latino Children Diagnosed with ASD and Their Families* was created through an extensive review of the literature, books, and weekly advising meetings.

The review of the literature was conducted utilizing Harley E. French Library and Chester Fritz Library databases through the University of North Dakota. Through these databases, supplementary databases used included: CINHALL, PubMed, Clinical Key, Academic Search Premier, DynaMed Plus, ERIC, PsychINFO, SCOPUS, and the American Occupational Therapy Association (AOTA). Key terms searched within these databases included: Latino, Hispanic, extended family, nuclear family, family network, Autism Spectrum Disorder, multigenerational, Family-Centered-Care, culture, psychosocial factors, symptoms, disability, occupational therapy and ASD, interventions, evidence-based interventions, coping skills, sensory, behavioral symptoms, culturally appropriate interventions for ASD, and occupational therapy interventions. Additionally, books were obtained from Casper College Library in Casper, Wyoming and were reviewed to determine key information to include in the product and literature review. Furthermore, academic textbooks were obtained to aid with identifying indispensable information to incorporate into the literature review and product.

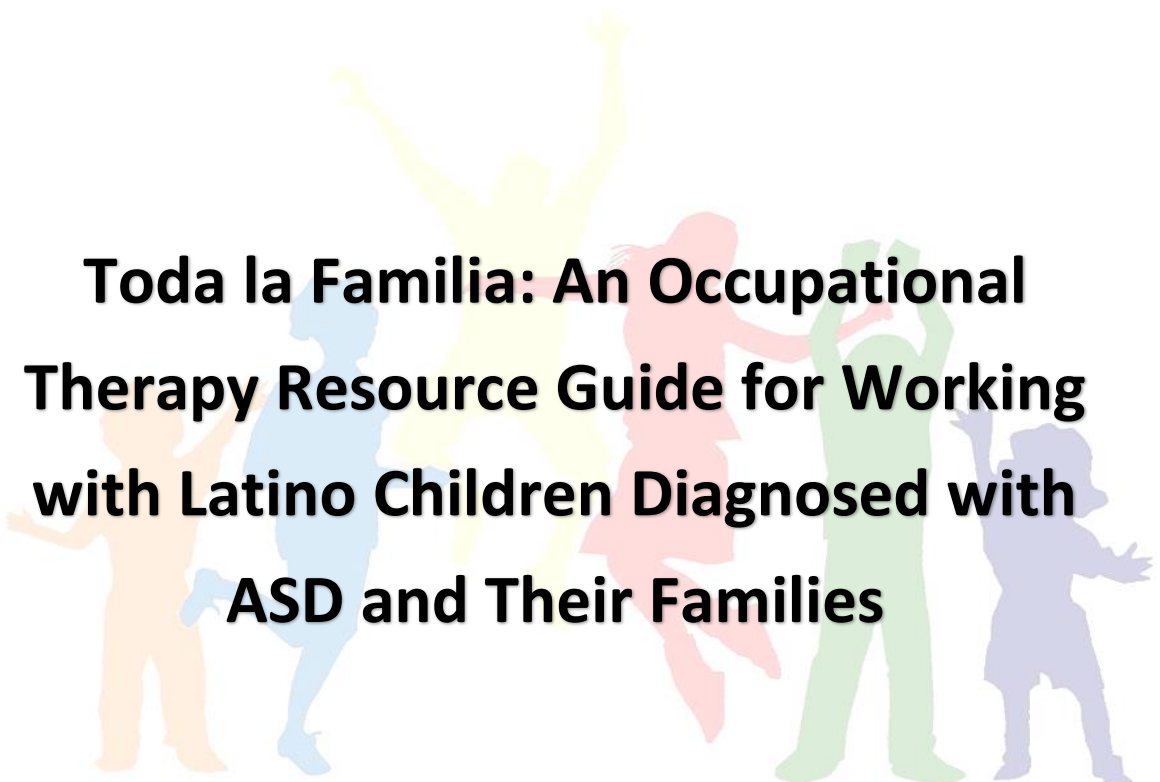
The journal articles were reviewed to determine validity, reliability, and appropriateness for the selected topic. Following the literature review, the project developers determined there was a gap in the literature regarding research on Latino extended families with a child diagnosed with ASD, culturally appropriate intervention, and incorporation of the family into interventions. During the literature review, the developers also selected Family Systems Theory and Ecology of Human Performance to guide the creation of the product. These theories became two key terms included in the research databases to produce additional literature needed to guide the creation of the product. Family Systems Theory produced the authors with vital information on family, culture, and dynamic relationships between an individual and their family. Likewise, EHP provided the authors with a theory that emphasized high importance on family context and the incorporation of the family into the therapeutic process. EHP was also utilized by the authors to provide occupational therapists with a model to incorporate into their therapeutic process with Latino families.

Once literature was reviewed and theories selected, the authors began creating the product. The authors included books and literature in the introduction of selected sections they felt required attention. Authors furthermore included reflective questions in specific sections to decrease bias in occupational therapists utilizing the resource guide. Lastly, authors began to create case scenarios incorporating all aspects of the product to provide therapists with holistic examples to aid them in practice, including simulated interventions utilizing the EHP model. The simulated scenarios are carried throughout the product and provide examples for each of the five intervention approaches included in EHP. Throughout this process, the authors met with advisors weekly to receive feedback

and guidance. Meetings transitioned from weekly to bi-weekly as the scholarly project neared conclusion.

## **CHAPTER IV**

### **Product**

A group of colorful silhouettes of people in various dancing or celebratory poses, including a child, an adult, and another child, set against a white background.

# **Toda la Familia: An Occupational Therapy Resource Guide for Working with Latino Children Diagnosed with ASD and Their Families**

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# Preface

“Occupational therapy maximizes health, well-being, and quality of life for all people, populations, and communities through effective solutions that facilitate participation in everyday living”  
(American Occupational Therapy Association, 2017)

The purpose of the resource manual is to provide occupational therapists with the tools necessary to provide culturally competent, family-centered, and holistic services to Latino children diagnosed with Autism Spectrum Disorder (ASD) and the extended family. Culture is embedded within the family system and guides attitudes, values, beliefs, and behaviors. Culture is integral to understanding the family dynamics and how the family functions as a unit. By allowing oneself to be open to understanding the culture of the family, one would then be able to optimize the child’s context to promote engagement in meaningful occupations.

Throughout this resource guide, the authors have incorporated three case scenarios that integrate the main concepts of this manual to demonstrate how these concepts may appear in the therapy context. The scenarios include both the family report and the clinical interpretation of the therapist when utilizing a culturally-sensitive and family-centered approach to the therapeutic process

# Terminology

The following terminology will assist occupational therapists in understanding key components of the manual. Additionally, comprehension of these terms will aid in the occupational therapy process of integrating these concepts into culturally competent, holistic, and family-centered care.

	Definition
<b>Autism Spectrum Disorder</b>	ASD is a neurodevelopmental disorder marked by deficits in social interaction and communication across several contexts and is characterized by impairments in social-emotional exchange, non-verbal communication, and development of relationships (American Psychiatric Association, 2013).
<b>Culture</b>	Attitudes, values, and beliefs shared by a group of people that influences behaviors (Mandell & Novak, 2005).
<b>Latino</b>	“A native or inhabitant of Latin America” (Morris, 1985, p. 717).
<b>Hispanic</b>	“Pertaining to the language, people, and culture of Spain, Portugal, or Latin America” (Morris, 1985, p. 613).
<b>Familismo</b>	Loyalty to the family that is associated with a strong sense of responsibility, dedication, and obligation to family members. (Bernal, Morales-Cruz, & Gomez Arroyo, 2016)
<b>Interdependence</b>	“Generally, a pattern of action and thought that focuses on the relationships between self and other(s) and emphasizes the importance of positive interpersonal behaviours such as cooperation” (Interdependence, 2009, para 1).
<b>Extended Family</b>	“A family unit making up one household that consists of parents, children, and other close relatives, such as grandparents or aunts” (Morris, 1985, p. 479).
<b>Nuclear Family</b>	“A self-contained family unit consisting of a mother and father and their children” (Morris, 1985, p. 851).
<b>Multigenerational Household</b>	Households that consist of three or more generations residing together (Lofquist, 2012). Examples of multigenerational households include: <ol style="list-style-type: none"> <li>1. The homeowner, child of the homeowner, and a grandchild of the homeowner.</li> <li>2. Includes a homeowner, a parent or in-law parent, a child of the homeowner, and a grandchild of the homeowner.</li> <li>3. Includes a homeowner, a parent or in-law parent, and a child of the homeowner. (Lofquist, 2012).</li> </ol>
<b>Family-Centered Care</b>	An approach to decision making between the healthcare professional and family (Kuo et al. 2012).



\*\*\* The term Latino and Hispanic are difficult for individuals to differentiate between. The term Hispanic was a “label” for individuals who spoke the native Spanish language. The term Hispanic felt too restrictive as it did not consider cultural norms or location of ancestry. Then the term Latino was adopted to allow for a more inclusive involvement and included individuals from Latin America descent. Individuals can identify as both Hispanic and Latino (Bullon & Alfonso, 2015). Bullon and Alfonso (2015) discuss that Latinos and Hispanics share cultural norms and belief systems, however, society does not typically differentiate the two terms all though they have two separate definitions. Multiple research studies have also used the two terms interchangeably. For this purpose, Latino and Hispanic are used interchangeably in this resource manual as they share common cultural norms. Additionally, one may choose to identify as one over the other or as both. \*\*\*

\*\*\*Extended family members include grandparents, aunts, uncles, and cousins. In Latino culture, the extended family is highly valued and included in aspects of daily life. Latinos’ typically value a collectivistic culture which values the distribution of family roles, child-care responsibilities, and the importance of family matters (Patcher & Dworkin, 1997). It is widely accepted and normal for Latino families to arrange themselves around an extended family network (Soto-Fulp & DelCampo, 1994). Multigenerational households are an example of families arranging themselves around one another. These types of households are described as three or more generations residing within a home including the homeowner, grandparents, and grandchildren (Kim, Spangler, & Gutter, 2016). For the purpose of this resource guide, when using the term multigenerational household, it is the expectation that the extended family is residing within the home. When discussing the topic of extended family or a multigenerational household these terms are correlated to one another within the family network. \*\*\*

## **Family-Centered Care**

Family-centered care (FCC) is complementary to the therapeutic process and must be implemented throughout the entire interaction between the family and the therapist. When a child and their caregiver first enter the therapy context, it is the job of the therapist to begin thinking about the child and their family as a unit. FCC is used to guide information gathering, rapport building, as well as, the inclusion of family in goal setting, treatment planning, and intervention implementation. Moving forward, these principles guide the therapeutic process and this approach should be embedded in all aspects of services being provided. This approach has also been identified as an effective approach to treating children with diagnosis (Dall’oglio et al., 2018; Kuo et al., 2012 American Academy of Pediatrics Committee on Hospital Care, 2003).

# Reflective Questions

**Define what family means to you?**

**How will you incorporate family in the therapeutic process?**

**What are steps you can take to remain unbiased towards the family?**

# Family Centered-Care

Family-centered care (FCC) is a model of pediatric practice used to help practitioners collaborate with family during decision-making and intervention planning. FCC is considered to be optimal healthcare and is typically associated with terms such as collaboration and partnership (Kuo et al., 2012). According to Dall'Oglio et al. (2018), family members are considered recipients of care when utilizing a FCC approach and therefore, benefit from participation, collaboration, and information sharing. Occupational therapy practitioners who use FCC in practice are able to obtain a comprehensive understanding of the family's needs including, social, spiritual, psychological, and physical factors (Dall'oglio et al., 2018).

When working with the extended family, the practitioner must utilize this approach in practice. It is essential that the practitioner be inclusive of family members outside of the nuclear family in order to respect a family's culture. Latino families recognize the importance of extended family and rely on these family members for support. For example, grandparents are able to provide a great deal of assistance, moral support, and a positive perspective (Melmed & Wheeler, 2015).

However, the occupational therapy practitioner may wonder exactly how to implement FCC while providing treatment. The existing literature suggests that FCC is non-specific and can be interpreted differently by different professions and professionals (Kuo et al., 2012; American Academy of Pediatrics Committee on Hospital Care, 2003). While a concrete definition of FCC has yet to be achieved (Kuo et al., 2012), the American Academy of Pediatrics Committee on Hospital Care has established core principles of FCC to integrate into practice.

## **Core Principles of Family-Centered Care**

1. Support and facilitate autonomy of the child and family about approaches to support and care.
2. Recognize and build on strengths of the child and family.
3. Respect the child and his or her family.
4. Honor differences such as cultural, ethnic, socioeconomic diversity and its effect of perspectives and experiences of care on the family.
5. Share unbiased and honest information with the family continually and in ways, they find to be affirming and useful
6. Provide formal and informal support to the child, parents, and guardians throughout the lifespan
7. Ensure flexibility in procedures and policies in order to meet the needs, beliefs, and cultural values of each child and family.

(American Academy of Pediatrics Committee on Hospital Care, 2003)

# Autism Spectrum Disorder

ASD is a neurodevelopmental disorder marked by deficits in social interaction and communication across several contexts and is characterized by impairments in social-emotional exchange, non-verbal communication, and development of relationships (American Psychiatric Association, 2013.)

According to the APA (2013), in addition to social interaction and communication deficits, a child diagnosed with ASD may present with repetitive and restricted behavior patterns. For example, repetitive and stereotyped motor movement, speech, or use of objects is common including, the act of lining up toys, echolalia, and flipping objects. The child may also be inflexible with routines and demonstrate ritualized patterns of behavior including eating the same food every day, extreme distress when small changes in routine occur, and difficulty with transitions. It is not uncommon that the child will have restricted interests and preoccupation with unusual objects. The child may also demonstrate hypo- or hyperactivity to sensory stimuli including being impervious to temperature/pain, extreme touching or smelling of objects, and fascination with movement or lights (APA, 2013).

<b>Severity Level</b>	<b>Communication</b>	<b>Behaviors</b>
<b>Level 1</b>	<ul style="list-style-type: none"> <li>● Deficits in social communication, without supports in place, cause observable impairments</li> <li>● Difficulty with initiating social interactions</li> <li>● Compared to typically developing children, may demonstrate a decreased interest in social interactions</li> </ul>	<ul style="list-style-type: none"> <li>● Rigid behaviors that cause significant interference in varying contexts</li> <li>● Trouble with a change in activity</li> <li>● Difficulty planning and organizing</li> </ul>
<b>Level 2</b>	<ul style="list-style-type: none"> <li>● Distinct deficits in non-verbal and verbal communication</li> <li>● Impairments in social interaction, even with supports in place</li> <li>● Initiation of social interactions are limited</li> <li>● Narrow special interests</li> </ul>	<ul style="list-style-type: none"> <li>● Restricted and repetitive behaviors present even to the casual observer</li> <li>● Distress occurs during a change of activity or focus</li> <li>● Inflexible behaviors present</li> </ul>
<b>Level 3</b>	<ul style="list-style-type: none"> <li>● Severe deficits in nonverbal and verbal social communication</li> <li>● Minimal response to others during social interaction</li> <li>● Few words, intelligible speech</li> <li>● Limited social interaction with others and only responsive to very direct approaches</li> </ul>	<ul style="list-style-type: none"> <li>● Extreme difficulty with changing focus or action</li> <li>● Change causes great distress</li> <li>● Inflexible behavior</li> <li>● Distinct repetitive and restricted behaviors</li> </ul>

(APA, 2013)

# Case Scenarios

## Case Scenario: Javier - Level 1 Severity

**Family Report:** “My son Javier is attending the 9th grade at a local high school. He was diagnosed with ASD when he was four and a half years old. When he was younger, he would babble, and my wife was the only one who could ever understand what he wanted or needed. He never even spoke an actual word until he was almost three years old. At home, he would watch his siblings play but never really participated with them. I remember he always had a difficult time when we would have to pick up toys and go take a bath. My wife always had to handle these situations. When things would change, he would cry and rock himself back and forth and I found it hard to calm him down, compared to his brother and sister. It seemed that he hated not knowing what was coming next and always seemed to make things more difficult. Now that he is older, he has started to interact with his siblings but only has one or two friends at school. He never really wants to talk about school, it’s always about cars otherwise, the conversation ends.” - *Pablo, Javier’s father*

**Clinical Interpretation:** Javier was unable to speak recognizable words until he was two and a half years old. Additionally, in unfamiliar social situations, he would avoid others and tend to isolate himself. Javier perseverates on his schedule and becomes agitated when routines change. Javier has an especially difficult time with transitions at school or home when they are unplanned. He has difficulty with expressive communication and initiating social interaction with his peers.



## **Case Scenario: Isabella - Level 2 Severity**

**Family Report:** “Isabella only began speaking around three years old. When she did start talking it would only be single words and never really made any sense. Even now she can only speak two to three words at a time. She becomes so obsessed with certain words like “itsy bitsy spider” and repeats this for days on end. She rarely smiles or appears to be having any fun. The school told me that she needed to be in a special classroom, five days a week. Her teacher told her mom and me that at school she will play alone and away from her peers. I always see her lining up her toys and if her cousin touches it, she becomes so upset and I just don’t understand why. It is overwhelming when she becomes upset because she will scratch herself and try to bite others or begin to rock herself back and forth. One time I picked her up late because I had to pick up her cousins first. The school called me to tell me that she was screaming, rocking back and forth, pulling her ear, and hitting others”. - *Elvira, Isabella’s grandmother.*

**Clinical Interpretation:** Isabella is an eight-year-old girl, who is diagnosed with ASD. Isabella only began speaking single words by the age of three and consistently had difficulty with expressive communication. Currently, Isabella is able to communicate using two to three-word sentences. While these sentences are intelligible, they typically do not pertain to the conversation. She will often perseverate on single sentences that provide a great amount of oral input. Isabella has difficulty at school playing with other children and is often seen playing alone and away from her peers. She rarely initiates social interaction with her peers and when others approach her, she becomes overwhelmed and acts out. Isabella demonstrates repetitive behaviors such as lining up toys or when in distress, rocking back and forth and pulling on her ear repeatedly.

### **Case Scenario: Theresa - Level 3 Severity**

**Family Report:** “Theresa just turned five, so I held her back from kindergarten and decided to send her next year instead. I enrolled her in a daycare just down the street from the house to help her make friends. But the teacher has told me that she never plays with others. She also told me that once when they were playing music, Theresa become extremely upset. She covered her ears and ran away from the teachers and hid from them. Sometimes at home when I am vacuuming, she will do the same thing. At night, her sister needs a nightlight, but Theresa hates it. She will start to scream and cry until I take her to my room. One thing that really bothers my mother is that Theresa will not make eye contact with others and ignores them. She always gets annoyed with Theresa because she has to show her how to do things over and over again. Whenever Theresa needs something rather than speaking, she just points at it and shakes her head up and down.”  
- *Esmerelda, Theresa’s mother*

**Clinical Interpretation:** Theresa is a five-year-old girl, who was recently diagnosed with ASD. Her family has just enrolled her into the daycare center down the street from her home. Theresa communicates with non-verbal gestures such as pointing to an object she wants, pushing away undesired items, and shaking her head up and down. Theresa will use one-word sentences sporadically. She becomes overstimulated with unanticipated sensory input including loud sounds and the visual environment. Her family provides maximal cueing to complete simple tasks. Theresa is inconsolable during great distress. When Theresa becomes overwhelmed and stressed, it is typical of her to elope or use maladaptive coping strategies, such as hiding, which was reported by the mother. Recently, there was an incident at daycare, and she eloped from the classroom and was found wandering by herself headed towards the direction of her home. Her family is concerned about what the appropriate next steps are moving forward.

## **Culture**

Culture is characterized as a set of patterns, beliefs, and attitudes shared by a group of people that influences their way of life (Ravindran & Meyers, 2011; Mandell & Novak, 2005). Often, these beliefs and behaviors are passed from generation to generation and embedded into the family dynamic (Mandell & Novak, 2005). Culture can influence how a family perceives an illness, selects treatment, and how to interact with the healthcare system.

# Reflective Questions

**What does culture mean to you?**

**What cultures are you familiar with?**

**What are your personal values and beliefs?**

**How does your culture impact the way you treat your clients?**

*Below is a list of cultural beliefs/norms of the Latino/Hispanic population identified through extensive research. This list is not representative of the whole culture and it is encouraged that the occupational therapist complete their own research on a specific culture.*

### **Refranes and Dichos**

- Popular sayings passed down from generation to generation. Typically, this term serves as an unwritten rule that the family abides by because it has been passed down throughout the years (Fallon & Quintana, 2015).

### **Familismo**

- Interdependence or family closeness. This term describes the act of sharing responsibilities such as helping with problem-solving, raising and disciplining children, and providing support among one another (Fallon & Quintana, 2015).

### **Simpatía**

- The cultural practice of avoiding conflict and controversy within the family in order to maintain harmony. A common saying in the Hispanic language is “Al hogar, como a la nave, le conviene la mar suave”. This saying translates to “for a home, as for a ship, calm seas are preferred” (Fallon & Quintana, 2015, p. 25). This advice on how to live life expresses the values of respect, agreement, and politeness within the family.

### **Personalismo**

- The importance of warmth within relationships and the value of interpersonal relationships in life. This value can be described as relating to others and the sense of belonging (Fallon & Quintana, 2015).

### **Respecto**

- The value of respect helps maintain and support simpatía, familismo, and personalismo. Respect is signified an emotional dependence unlike the English version of the word. Respect is deeply rooted in the understanding of family and interpersonal relationships (Fallon & Quintana, 2015).

**Obediencia**

- Obedience relates to the parental authority. Obedience acts as the framework and support of parental authority through which family values are instilled. In the Hispanic culture, children are taught to respond to their elders using submissive phrases such as “a sus ordenes” or “para servirle” (Fallon & Quintana, 2015, p. 26) out of both respect and obedience to the hierarchical standard.

**Machismo**

- Attitudes and beliefs associated with the male role in both the family and the community. This term can be viewed as either a negative or a positive. In the positive light, Machismo refers to being confident, personable, and responsible. However, it can also refer to the male being aloof, aggressive, or risk-taking (Fallon & Quintana, 2015).

**Marianismo**

- The term used to describe humility and virtue that is often expressed through caregiving and the devotion to the Virgin Mary (Fallon & Quintana, 2015).

**Fatalismo**

- This term depicts the belief that what occurs in life is fate and that one cannot change the trajectory of their destiny (Mandell & Novak, 2005).

# Case Scenarios

## Case Scenario: Javier - Level I Severity

**Family Report:** “My son and I have a hard time getting along. I really wish he would watch fútbol with me and he always refuses. We don’t have a lot of the same interests and I get frustrated with that a lot. Javier has never expressed much interest in girls, so we don’t even have that to talk about. Something else that bothers me is he always lets his sister push him around and he’s soft. I mean my dad would get frustrated with me and ignore me when I was a “softy” - *Pablo, Javier’s father*

**Clinical Interpretation:** It appears that Javier’s father is struggling with the cultural concept *machismo*. This cultural concept characterizes the male role in the family and expects that males be responsible, demand respect, and be confident. The father may be aloof to Javier’s diagnosis and what it entails because he is more focused on his son’s lack of “masculine” qualities. Due to Javier’s limited interests, it may be difficult for his dad to find a connection with him. As a result, *familismo* could be negatively impacted and disrupt the concept of interdependence.

## Case Scenario: Isabella - Level 2 Severity

**Family Report:** “When I tried to tell my mom about my concerns for Isabella, she was hesitant to believe me. Once, when the three of us were at the store before Isabella was diagnosed, Isabella began to scream and cry. Neither of us could figure out what she wanted, so I started to console her and tried to buy her things. My mom watched this happen and later told me that my daughter is badly behaved and seems spoiled. We got into a huge fight so after that, she rarely said anything else. I also remember that once Isabella was diagnosed, my sisters would always tell me “It will be fine” or “God made her this way for a reason”. Sometimes it can be really hard to get along, especially all living under the same roof.” - *Serena, Isabella’s mother.*

**Clinical Interpretation:** It appears that Isabella’s family has strong cultural beliefs regarding *simpatía* and *fatalismo*. Isabella’s family members keep referring to fate as the reason for Isabella’s diagnosis of ASD (*fatalismo*). Which resulted in conflict within the family. Isabella’s mother has expressed that her family’s beliefs often held her back from seeking services because she didn’t want to cause conflict or controversy (*simpatía*).



### **Case Scenario: Theresa - Level 3 Severity**

**Family Report:** “Sometimes when Esmerelda is working, I will watch Theresa for her. The other day we were at the house and my mom wanted Theresa to pick up her toys. Theresa seemed to ignore her and kept playing. I saw my mom becoming upset and start to get mad at Theresa. So, she asked her again to pick up her toys, but Theresa didn’t respond to her. Eventually, my mom became so frustrated she started yelling at Theresa which, made her scream and cry. I tried to calm her down, but it felt impossible. In the house there is a lot of tension between us, my mom expects the grandkids to respond with “Mande”, which means yes. But Theresa can’t talk so it causes tension.” - *Flora, Theresa’s aunt*

**Clinical Interpretation:** It appears that Theresa’s grandmother values obedience and respect from her grandkids. Theresa is unable to communicate with her grandmother which puts a strain on the family. When she expects her to respond with “Mande” she is demonstrating the cultural value of *obediencia*. In Latino culture, it is expected that children respond to parental authority using submissive phrases. It also appears that interpersonal relationships within the family are struggling which makes maintaining respect (*respecto*) with one another difficult.

## **Theory**

Theory is a critical component in guiding the therapeutic process and providing evidence to the profession as a whole. Theory contains assumptions and principles that guide the therapist in interacting with the client, providing interventions, and obtaining outcomes (Cohn & Coster, 2014). Theory accomplishes this by explaining concepts and/or events that help predict behaviors and relationships (Cole & Tufano, 2008). It is important to understand that not one theory fits every population and that occupational therapists need to select theories that meet the needs of their diverse clientele.

## **Reflective Questions**

**What are your perceptions and experiences of using theory-based practice?**

**What theories, models, and frame of references are most familiar with?**

**What is your current knowledge base on the Ecology of Human Performance (EHP)?**

## **Family Systems Theory**

Bowen's Family system theory contains eight concepts in understanding a family as an emotional unit (Kerr, 2000). The following eight concepts are defined to give the occupational therapist a further understanding of the concepts and how they are used to comprehend family dynamics and assist with implementing effective family-centered care.

# Family Systems Theory Principles

## 1. Triangles

- a. Tensions transfers between relationships within a triangle.
- b. One man out: how long can an individual withstand looking in from the outside?
- c. The outsider role is desired when too much tension is occurring within the triangle relationship.

## 2. Differentiation of Self

- a. An individual's ability to remove feelings from thought process and think logically.
- b. Maintain one's sense self.

## 3. Nuclear Family Emotional Process

- a. Problems typically arise from:
  - i. Marital conflict
  - ii. Dysfunction in one spouse
  - iii. Impairment of one or more children
  - iv. Emotional distance

## 4. Family Projection Process

- a. How family projects emotional responses to children

## 5. Multigenerational Transmission Process

- a. Emotional responses transferred from generation to generation.

## 6. Emotional cutoff

- a. Complete or partial departure from the family unit due to strained relationships with family members. Problems not resolved but more simply ignored.

## 7. Sibling position

- a. Sibling position assisted in determining the expected role that family members were expected to undertake

**8. Societal emotional process**

- a. How social context influence emotional responses with a given family member. Coping strategies passed down through family projection.

(Dykeman, 2016; Walsh, 2009; Kerr, 2000)

# Case Scenarios

## Case Scenario: Javier - Level 1 Severity

### Clinical Application:

- Principle 1 - Triangles
  - Javier's father appears to be on the outside looking in. Javier and he don't have the same interest and are losing the sense of a father-son relationship.
  
- Principle 3- Nuclear Family Emotional Process
  - Impairment of one or more children
    - Javier was diagnosed with ASD at 4 ½ years old which has influenced the family unit.
  
- Principle 5 - Multigenerational Transmission Process
  - Pablo is responding to Javier the way his father responded to him, by getting frustrated or ignoring him when they have nothing to talk about or when Javier appears "soft".

## **Case Scenario: Isabella - Level 2 Severity**

### **Clinical Application:**

- Principle 3- Nuclear Family Emotional Process
  - Impairment of one or more children
    - Isabella was diagnosed with ASD around 3-years-old which has influenced the family unit.
  
- Principle 6 - Emotional cutoff
  - This is apparent in the relationships between grandmother, aunts, and mother. Mom is beginning to distance herself due to her family's beliefs on the child's behavior.
  
- Principle 7 - Sibling position
  - It was identified that Isabella is the oldest of the children which has influenced her younger sister to take on a caretaker role at a young age.
  
- Principle 8 - Societal emotional process
  - Culture and society have influenced how family members are responding to Theresa and her mother. The grandmother has stated that the child is spoiled while Theresa's aunts have stated that it was fate for Theresa to be diagnosed with ASD.



## **Case Scenario: Theresa - Level 3 Severity**

### **Clinical Application:**

- Principle 2 - Differentiation of Self
  - Theresa's grandmother is having a difficult time thinking logically when it comes to how Theresa should respond to her. Theresa cognitively cannot respond with the term "Mande" but it appears to still bother grandmother.
  
- Principle 3- Nuclear Family Emotional Process
  - Impairment of one or more children
    - Theresa is a five-year-old girl recently diagnosed with ASD which has influenced the family unit.
  
- Principle 4 - Family Projection Process
  - Theresa's grandmother projects her frustration negatively onto Theresa as evidence by the grandmother yelling at Theresa and causing distress to the child.

## **Ecology of Human Performance**

A second theory, Ecology of Human Performance (EHP), was chosen to supplement the Family System Theory and provide the addition of an occupational therapy perspective. According to Turpin & Iwama (2011), a key feature of this theory is the significance of the context and environment. Research on the Latino culture has recognized the importance of the family context, specifically extended-family as an integral cultural component in the Latino population (Hardwood et al., 2002). Through the lens of EHP, the practitioner is able to integrate the family into the therapeutic process due to its emphasis on context and how context impacts behaviors. When using EHP to guide the therapeutic process, the concept of the environment shapes how people view themselves and what they do. Additionally, occupational therapists are equipped with the skills to understand the interdependent relationship between the person and the context (Turpin & Iwama, 2011).

EHP uses language that is universal and easily understood by other professions. Additionally, the language used helps the practitioner to expand their views of the terminology used. For example, EHP includes social, physical, temporal, and cultural aspects in the term context.

# Assumptions of EHP

1. The individual and their contexts are both unique and dynamic.
  - a. The context influences the person and the person influences context.
  - b. The transaction between the context and the person determines a person's performance range.
  - c. A transactional relation is present between the person and the context.
2. A fixed environment is different than a natural environment.
  - a. Contrived contexts yield different performance outcomes compared to the natural context.
  - b. Performance is best determined in the natural environment.
3. Occupational therapy practice is focused on the inclusion of persons with disabilities in all areas of society and promoting self-determination.
  - a. The therapeutic process begins when the person or the family identify what the individual needs or wants.
  - b. Occupational therapy practice includes adapting or altering systems so that persons with disabilities receive their full rights and privileges
4. Independence is achieved when the person's needs and wants are met.
  - a. Independence can still be achieved if the person requires assistive devices or caregivers.
  - b. Alter and Adapted intervention approaches are only used when restorative interventions have failed.

## Core Constructs

<b>Person</b>	<p>An individual with an exclusive configuration of experiences, abilities, cognitive, psychosocial, and sensorimotor skills.</p> <ul style="list-style-type: none"> <li>● The individual is complex and unique.</li> <li>● Contextual variable and meaning the person attaches to a task influence performance</li> </ul> <p>(Dunn, 2017)</p>
<b>Task</b>	<p>An objective set of behaviors that allow a person to achieve a goal.</p> <ul style="list-style-type: none"> <li>● An infinite amount of tasks exist around each individual</li> <li>● A task can be defined differently from person to person and meaning of the task is directly influenced by personal experience and cultural context.</li> </ul> <p>(Dunn, 2017)</p>
<b>Context</b>	<p>Context refers to the set of interconnected conditions that surround an individual.</p> <ul style="list-style-type: none"> <li>● Temporal context             <ul style="list-style-type: none"> <li>○ Life cycle</li> <li>○ Chronological age</li> <li>○ Development stage</li> <li>○ Health status</li> </ul> </li> <li>● Social Context             <ul style="list-style-type: none"> <li>○ Family</li> <li>○ Friends</li> <li>○ Clubs</li> <li>○ Organizations</li> </ul> </li> <li>● Cultural Context             <ul style="list-style-type: none"> <li>○ Ethnicity</li> <li>○ Religion</li> <li>○ Any factor that contributes to a person's sense of identity</li> </ul> </li> <li>● Physical Context             <ul style="list-style-type: none"> <li>○ Natural</li> <li>○ Contrived</li> <li>○ Objects within the environment</li> </ul> </li> </ul> <p>(Dunn, 2017)</p>

<b>Performance</b>	<p>The process of interacting with the environment to engage in a task.</p> <ul style="list-style-type: none"><li>● The use of skills and abilities</li><li>● Performance range<ul style="list-style-type: none"><li>○ Dependent on context variables, personal motivation, and person factors.</li></ul></li></ul> <p>(Dunn, 2017)</p>
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# EHP Intervention Approaches

There are five therapeutic approaches to intervention under the EHP framework. Each approach carefully considers the context, person, and task. According to Dunn (2017), the ultimate goal of each intervention approach is to support the interests of the individual and performance needs.

The first intervention approach is **Establish/Restore**. This approach focuses on person factors and the goal is to improve a person's abilities and capabilities. Context is influential in the availability of tasks and can either provide or inhibit performance.

The second intervention approach is **Alter**. This method is used when the therapist focuses on the context in which the client(s) performs. The occupational therapy practitioner will need to understand the features of a particular context and the activity demands to find the best match between the client and their current abilities. This intervention approach emphasizes context options that are available and how the context impacts performance.

A third intervention approach is **Adapt/Modify**. This method of intervention focuses on changes within the environment to support performance. When using this approach, the therapist can either make adjustments to the task features or aspect of the environment.

**Prevention** is the fourth intervention approach under the EHP framework. This approach aims to prevent the development of performance challenges. The therapist can use this method by changing the context, task variables, or the person in order to avoid negative outcomes.

The fifth intervention approach is **Create**. This method of intervention aims to create circumstances that support performance for persons with or without a disability. This intervention approach does not assume that there is a problem but rather focuses on maximizing a person's full potential by targeting the context, the task, the person, or a combination of variables.

(Dunn, 2017)

# Therapeutic Reasoning

There are six basic steps that should be followed to guide the therapeutic process of evaluation and intervention through the lens of EHP.

1. Determine the wants and needs of the individual, as well as, their priorities.
2. Analyze the person's most important tasks (Task Analysis).
3. Evaluate the individual's performance.
4. Evaluate the contexts that the client interacts with.
5. Evaluate the client's person factors and how they either hinder or support performance.
6. Develop goals that are prioritized and choose intervention methods to support performance within the context.

(Dunn, 2017)

## **Evaluation**

The purpose of this guide is to facilitate cultural competency and family-centered care for practitioners working with Latino families and their child diagnosed with ASD. The therapeutic process includes evaluation, intervention, and outcomes. In an aim to address both the child and the family, it is essential that the practitioner use evaluation tools that consider a wide variety of person factors. This will then enhance the practitioner's understanding of the child and their families.



## **Reflective Questions**

**What assessments are currently being used at your facility?**

**What assessments do you feel comfortable in administering?**

**What assessments allow for family input?**

**How could the assessment tools you are currently using be incorporated into a family-centered and culturally sensitive approach to services?**

## Evaluation Tools

The assessments provided below are examples of assessments that can assist the practitioner in gaining valuable information on the client and their family. These assessment tools may be useful in obtaining information on the parent, the child, or environmental factors that are influential in the daily lives of the family. This is not an extensive list and is recommended that practitioners use their clinical-reasoning and explore assessments they feel will be relevant in obtaining information on the client and their families.

<b>Client</b>	
<b>Assessment</b>	<b>Description</b>
<b>Canadian Occupational Performance Measure (COPM)</b>	This standardized assessment allows the therapist to gain knowledge on how a client perceives their occupational performance over time. The assessment can identify problem areas, client’s priorities, and satisfaction. The COPM can also aid the therapist in goal-setting and measuring change to match interventions. This assessment is appropriate for ages (Law et al., 2014)
<b>Children Assessment of Participation and Enjoyment/Preference for Activities (CAPE)</b>	The CAPE is used to explore the child’s day-to-day participation in a variety of activities. Activities considered can include recreational, social, skills-based, and self-improvement. Information gathered from the tool is then used to guide intervention and outcomes. This tool is appropriate for individuals aged 6-21 and can be used whether or not a disability is present (King et al., 2004).
<b>Sensory Processing Measure (SPM)</b>	A norm-referenced assessment that gathers information about a child’s sensory processing/integration patterns and its impact on a child’s behavior and participation in multiple contexts including home, community, and/or school (Parham & Ecker, 2007).
<b>Sensory Profile 2 (Child &amp; School Companion Sensory Profiles)</b>	A questionnaire focused on capturing a child sensory processing pattern by reports from caregiver, and/or teacher. This sensory processing pattern provides information to the healthcare profession on how these patterns may impede or facilitate participation. This

	questionnaire is appropriate for children aged 0 through 14 years (Dunn, 2014)
<b>Peabody Developmental Motor Scales</b>	A standardized assessment that assesses fine motor (grasping, visual-motor integrations) and gross motor (reflexes, stationary, locomotion, and object manipulation) abilities in children birth through five years (Folio & Fewell, 2000). This assessment will assist the practitioner in identify strengths and areas for improvement to increase engagement in occupations.
<b>Bruininks-Osertysky Test of Motor Proficiency (BOT-2)</b>	The BOT-2 is an assessment that measures a variety of motor skills, through engaging activities, for individuals between 4 and 21 years of age. The BOT-2 addresses fine motor precision, fine motor integration, manual dexterity, bilateral coordination, balance, running speed and agility, upper-limb coordination, and strength (Bruininks & Bruininks, 2005)
<b>Paediatric Activity Card Sort (PACS)</b>	This occupation-based visual assessment tool focuses on a child's self-report of their perception of their performance in typical childhood occupations. This tool is appropriate for ages 5-14 and individuals in this age level that can respond to the corresponding pictures and questions (Mandich, Polatajko, Miller, & Baum, 2004).
<b>The Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery VMI)</b>	This assessment is aimed to address the level in which an individual can integrate their motor and visual capabilities. This assessment is appropriate for ages 2-100. "This assessment is culturally sensitive as they use geometric shapes instead of letters and numbers as those can vary depending on the background" (Beery & Beery, 2010, p. 1)
<b>Clinical Observation of Motor and Postural Skills (COMPS)</b>	The COMPS is a screening tool to assist occupational therapist observations in identify motor impairments, absences, and/or deficits. The COMPS is categorized into six items; slow movements, rapid forearm rotations, finger-nose touching, prone extension posture, asymmetrical tonic neck reflex and supine flexion posture. This screening tool is appropriate for ages 5-16. This assessment is not appropriate for children with neuromotor problems such as cerebral palsy and epilepsy (Wilson, Pollock, Kaplan & Law, 2000).
<b>Interest Checklist</b>	This tool allows the therapist to identify a client's strength and interests in activities. This tool looks at activities an individual has completed in the past, participates in the

	present, and/or may enjoy to pursue in the future (Matsutsuyu, 1969).
<b>Family</b>	
<b>Assessment</b>	<b>Description</b>
<b>Childhood Autism Rating Scale-Parent version</b>	A self-report measure that is used to assess a parent's experiences of their child's level of functioning. This tool was adapted from the Childhood Autism Rating Scale (CARS). There are 14 domains and severity is based on a 4-point scale ranging from 1-4 for chronological age, as well as, a 4-point scale ranging from none at all -1 to extreme - 4 (Tobing & Glenwick, 2002).
<b>Epidemiological Studies Depression Scale</b>	This assessment focuses on caregivers' emotions and responses experienced over the last week. This 20-item assessment is sensitive to caregivers and non-caregivers and can provide occupational therapists more insight on how a family is coping with stress. This assessment has been found to be used with diverse backgrounds (American Psychological Association, 2018).
<b>Depression Anxiety Stress Scale (DASS)</b>	DASS is a self-report scale designed to assess the negative emotional states of anxiety, stress, and depression. This tool was constructed to aid the practitioner in understanding clinically significant emotional states. This evaluation tool focuses on the core symptoms of anxiety, stress, and depression such as the inability to experience enjoyment or satisfaction, the worry of loss of control, or the inability to relax. This tool has been translated into Spanish (Psychology Foundation of Australia, 2018).
<b>Family Adaptability and Cohesion Evaluation Scale-IV</b>	An evaluation tool that measures family functioning using six subscales to evaluate cohesion and flexibility within the family. The evaluation tool is 42 items in which the client rates the degree to which they agree on a 5-point scale (1 = totally disagree, 5 = totally agree). This tool can be used in either English or Spanish (Martínez-Pampliega, Merino, Iriarte, & Olson, 2017).
<b>The Parenting Sense of Competence Scale</b>	The Parenting Sense of Competence Scale is utilized to measure and evaluate a parent's perceived parenting ability. The 17-item assessment tool has two subscales

	including Skills/Knowledge and Valuing/Comfort. The items are rated on a 6-point Likert Scale from 1-strongly disagree to 6- strongly agree (Karp, Lutenbacher, & Wallston, 2015).
<b>The Beach Center on Disability Family Quality of Life Scale</b>	A tool designed to assess several aspects of families' perceived satisfaction related to the quality of life. This tool measures family interaction, parenting, emotional well-being, physical/material well-being, and disability related support (Beach Center on Disability, 2012). This tool can then be used to guide intervention and assess the needs of the family.
<b>Environment</b>	
<b>Assessment</b>	<b>Description</b>
<b>Interpersonal Support Evaluation List</b>	The Interpersonal Support Evaluation List is an evaluation tool used to measure perceptions of social support among individuals. It is 40 item tool that considers a person's response to stressful events. There are 4 subscales including, appraisal and support, tangible support, belonging support, and self-esteem support (Measurement Instrument Database for the Social Sciences, 2018).
<b>School Function Assessment (SFA)</b>	An assessment tool utilized to measure social aspects and task performance in the academic context for children attending K-6 grade. The questionnaire assessment is filled out by a school professional that has observed the student in the academic context. The SFA measures three primary components (participation, task support, and activity performance) and is a valuable tool in implementing Individualized Education Plans (IEP) and cohesion in the academic environment (Coster, Deeney, Haltiwagner & Haley, 1998).

<b>Life Stressors and Social Resources Inventory</b>	An assessment tool used to measure ongoing life stressors, as well as, social resources and how they change over time. Practitioners may use this tool to describe a person's life contexts, compare an individual to a group, monitor stability and changes, and examine how life events impact an individual's functioning. This tool is for adults 18 years and older and covers eight areas of life experiences (Psychological Assessment Resources, 2018).
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## **Intervention**

When following this manual, the goal of intervention is to improve child outcomes, as well as increase family participation and cohesion. As the therapist, it is your responsibility to ensure that interventions are evidence-based, family-centered, and culturally appropriate. In this portion of the manual, you will find evidence-based interventions and literature to support each one to facilitate evidence-based practice.

## Reflective Questions

**What interventions are you currently using in practice with children who have a diagnosis of ASD?**

**Identify strategies you have used to incorporate family into interventions for children with ASD.**

**Do you believe that if you modify an intervention for cultural practice, that it upholds the evidence- base, and why?**



## Evidenced-Based Interventions

A diagnosis of ASD within the family can bring confusion, disagreement, and a variety of other challenges to the child and their family. Research suggests that evidence-based interventions may not be congruent to cultural values when being implemented with Latino children (DuBay, Watson, & Zhang, 2017). Parents have reported that at home they are unsure how to interact with their child and blame this on lack of support from healthcare providers. One parent described her experience having little to no communication with the provider but wanted to be more involved (DuBay, Watson, & Zhang, 2017).

Therefore, the implementation of a family-centered approach to care that is culturally sensitive is essential. The practitioner must realize the importance of occupation-centered, culturally sensitive, and family-centered intervention. Research has identified that interventions that align with cultural values and expectations of the family yield positive outcomes and are likely to increase participation in treatment (DuBay, Watson, & Zhang, 2017). Failure to provide culturally sensitive intervention has potential to result in strain on social relationships within the family, failure to comply with recommendations, and discontinuation of services (DuBay, Watson, & Zhang, 2017). Therefore, moving forward it will be essential to incorporate family-oriented intervention into the treatment plan.

Parent-mediated intervention is an approach to treatment that aims to include the parents or caregivers in the therapeutic process. This approach to intervention aims to teach caregivers to deliver intervention strategies to their child with ASD in order to increase knowledge and self-efficacy (Magaña, Lopez, & Machalicek, 2017; Pickard, Kilgore, & Ingersoll, 2016). Parent-mediated intervention has been found to empower caregivers and reduce stress and depression (Pickard et al., 2016). Additionally, this approach to intervention facilitates improved generalization of skills over time and allows for engagement in a variety of contexts (DuBay, Watson, & Zhang, 2017). This intervention method has the potential to be adapted to the caregiver(s) of the child and expanded to include extended family such as grandparents, aunts, and uncles, or cousins. According to DuBay, Watson,

& Zhang (2017), parent-mediated intervention also has the potential to be cost-effective and is often favored by families.

Below are articles that present an evidence-base for interventions that are currently being implemented in practice for children with ASD. This is not an extensive list and the product developers suggest you conduct your own literature review on evidence-based interventions.

Intervention	Evidence
Activities of Daily Living	<p>Hong, E. R., Ganz, J. B., Ninci, J., Neely, L., Gilliland, W., &amp; Boles, M. (2015). An evaluation of quality of research on evidence-based practices for daily living skills for individuals with autism spectrum disorder. <i>Journal of Autism Developmental Disorder</i>, <i>45</i>, 2792-2815. doi:10.1007/s10803-015-2444-3</p> <p>McCollum, M., LaVesser, P., &amp; Berg, C. (2016). Participation in daily activities of young adults with high functioning autism spectrum disorder. <i>Journal of Autism Developmental Disorder</i>, <i>40</i>, 987-997. doi:10.1007/s10803-015-2642-z</p> <p>Weaver, L. L. (2015). Effectiveness of work, activities of daily living, education, and sleep interventions for people with autism spectrum disorder: A systematic review. <i>American Journal of Occupational Therapy</i>, <i>69</i>(5), 1-21. doi.org/10.5014/ajot.2015.017962</p> <p>Wertalik, J. L., &amp; Kubina, R. M. (2016). Interventions to improve personal care skills for individuals with autism: A review of the literature. <i>Review Journal of Autism Developmental Disorders</i>, <i>4</i>(1), 50-60. doi:10.1007/s40489-016-0097-6</p>
Applied Behavioral Analysis	<p>Mohammadzaheri, F., Koegel, L. K., Mohammad, R., Rafiee, S. M. (2014). A randomized clinical trial comparison between pivotal response treatment (PRT) and structured applied behavior analysis (ABA) intervention for children with autism. <i>Journal of Autism Developmental Disorders</i>, <i>44</i>(11), 2769-2777. doi:10.1007/s10803-014-2137-3</p> <p>Rodriguez, A. N., Hernandez, Y., Guzmán, G., Jiménez Martínez, M. C., Guzman G., Hernandez, Y., Nunez, A. L. (2017). Analysis of applied behavior treatment for children with autism spectrum disorder. <i>European Psychiatry</i>, <i>41</i>, S218-S218. doi:10.1016/i.eurpsy.2017.01.2202</p>

	<p>Welch, C. D., &amp; Polatajko, H. J. (2016). The issue is - Applied behavior analysis, autism, and occupational therapy: A search for understanding. <i>American Journal of Occupational Therapy</i>, 70, 7004360020. doi.org/10.5014/ajot.2016.018689</p>
Coping Skills	<p>Rayan, A. &amp; Ahmad, M. (2016). Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder. <i>Research in Developmental Disabilities</i> 55, 185-196. <a href="https://doi.org/10.1016/j.ridd.2016.04.002">doi.org/10.1016/j.ridd.2016.04.002</a></p>
Developmental Skills	<p>Case-Smith, J., &amp; Arbesman. (2008). Evidence-based review of interventions for autism used in or of relevance to occupational therapy. <i>American Journal of Occupational Therapy</i>, 62(4), 416-429. doi:10.5014/ajot.62.4.416</p> <p>Whitehouse, A. J. O., Granich, J., Alvares, G., Busacca, M., Cooper, M. N., Dass, A., ... Anderson, A. (2017). A randomised controlled trial of an iPad-based application to complement early behavioural intervention in autism spectrum disorder. <i>Journal of Child Psychology &amp; Psychiatry</i>, 58(9), 1042–1052. doi:10.1111/jcpp.12752</p>
Parent-Mediated	<p>BuZhardt, J., Rusinko, L., Heitzman, P. L., Trevino, M. S., &amp; McGrath, A. (2016). Exploratory evaluation and initial adaptation of a parent training program for Hispanic families of children with autism. <i>Family Process</i>, 55(1), 107–122. doi-org.ezproxy.library.und.edu/10.1111/famp.12146</p> <p>Case-Smith, J., &amp; Arbesman. (2008). Evidence-based review of interventions for autism used in or of relevance to occupational therapy. <i>American Journal of Occupational Therapy</i>, 62(4), 416-429. doi:10.5014/ajot.62.4.416</p> <p>DuBay, M., Watson, L. R., &amp; Zhang, W. (2017). In search of culturally appropriate autism interventions: Perspectives of Latino caregivers. <i>Journal of Autism Developmental Disorders</i>, 48, 1623-1639. doi:10.1007/s10803-01703394-8</p> <p>Magaña, S., Lopez, K., &amp; Machalicek, W. (2017). Parents taking action: A psycho-educational intervention for Latino parents of children with autism spectrum disorder. <i>Family Process</i>, 56(1), 59–74. doi.org/10.1111/famp.12169</p>

	<p>Rayan, A. &amp; Ahmad, M. (2016). Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder. <i>Research in Developmental Disabilities</i> 55, 185-196. <a href="https://doi.org/10.1016/j.ridd.2016.04.002">doi.org/10.1016/j.ridd.2016.04.002</a></p>
Behaviors	<p>Hwang, Y.-S., Kearney, P., Klieve, H., Lang, W., &amp; Roberts, J. (2015). Cultivating mind: Mindfulness interventions for children with autism spectrum disorder and problem behaviours, and their mothers. <i>Journal of Child &amp; Family Studies</i>, 24(10), 3093–3106. <a href="https://doi-org.ezproxy.library.und.edu/10.1007/s10826-015-0114-x">https://doi-org.ezproxy.library.und.edu/10.1007/s10826-015-0114-x</a></p> <p>Kuhaneck, H. M., Madonna, S., Novak, A., &amp; Pearson, E. (2015). Effectiveness of interventions for children with autism spectrum disorder and their parents: A systematic review of family outcomes. <i>American Journal of Occupational Therapy</i>, 69, 6905180040. doi.org/10.5014/ajot.2015.017855</p> <p>Tanner, K., Hand, B.N., O’Toole, G. &amp; Lane, A.E. (2015). Effectiveness of interventions to improve social participation, play, leisure, and restricted and repetitive behaviors in people with autism spectrum disorder: A systematic review. <i>American Journal of Occupational Therapy</i>, 69(5), 1-48. doi.org/10.5014/ajot.2015.017806</p>
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## **Clinical Application**

You have now been provided with information on primary concepts necessary to implement family-centered and culturally sensitive care in the Latino extended family context. This section of the manual will integrate each concept into the therapeutic process that aligns with the EHP model.

## **Obtaining a family and culturally sensitive Occupational Profile**

1. Who interacts with your child on a given day?
2. Tell me about a typical day for your child and your family?
3. Does your family have routines that help structure your child's day?
4. Are there any cultural preferences you want us to be aware of?
5. Who are the people that are involved in your child's life?
6. Tell me about your experiences of raising a child with ASD.
7. Who is involved in caring for your child?
8. What are your spiritual values and how do they impact your daily life?
9. Do you have people in your daily life that are there to support you?
  - Who are they, and how do they support you?
10. How do you feel your child's diagnosis has impacted your family?
11. What are the different roles of your family members?
12. How do these roles impact your family or child with autism?
13. What holiday(s) does your family celebrate?
14. When your child/grandchild was diagnosed with autism, what were your thoughts and feelings?
15. How do you define your own culture?
16. Let's go back to when you or your family member started having concerns about your child, tell me about them?

(Wake Forest University, n.d.)

# Case Scenario: Javier - Level I Severity

## Occupation Based Assessment

Using EHP to guide the assessment, the practitioner would begin by interviewing the family, Javier, and Javier's teachers (Dunn, 2017). Next, the practitioner would observe Javier in a variety of contexts pertaining to Javier and his family (Dunn, 2017). For Javier, the assessments chosen included the Sensory Profile 2 (SP2) to gain an understanding of how his sensory patterns impact occupations. The Canadian Occupational Performance Measure (COPM) was also used to gain an understanding of how the client perceives their occupational performance. The COPM was also used with the family to determine their perception of their child's performance and determine if perceptions varied. This assisted the occupational therapist in identifying and prioritizing client and family goals. The last assessment utilized was the Interest Checklist to gain a better understanding of Javier's interest as Javier's father reported a lack of connection with son due to limited interests.

### Family & Client Goals

1. Increase Javier's interest and social participation.
2. Improve the father and son relationship (*Principle 1 of Family Systems Theory*) (*personalismo*).
3. Increase Javier's independence to reduced caregiver burden on mother.



Contexts			
Physical	Social	Cultural	Temporal
<ul style="list-style-type: none"> <li>○ Javier lives in an urban community.</li> <li>○ Javier attends high school in a normal classroom.</li> <li>○ Javier and his family live in a four-bedroom house.</li> <li>○ Javier identified 8/10 on importance of personal-care but satisfaction score was 3/10 (COPM)</li> </ul>	<ul style="list-style-type: none"> <li>○ Javier has two friends at school.</li> <li>○ Javier doesn't interact with his youngest sibling.</li> <li>○ It appears that Javier connects more with his mother.</li> <li>○ Javier likes to collect old fashioned car models and figurines (Interest Checklist).</li> <li>○ Javier enjoys talking about cars and he can sometimes persevere on particular things.</li> <li>○ Javier's father wants to connect more with his son (<i>personalismo</i>).</li> <li>○ Javier likes to watch movies and would like to watch more movies (Interest Checklist).</li> </ul>	<ul style="list-style-type: none"> <li>○ Hispanic</li> <li>○ Lives with his parents, two siblings, and grandparents (<i>familismo, multigenerational home</i>).</li> <li>○ Father has gender-specific roles he feels his son should participate in (<i>Principle 5 of Family Systems Theory machismo</i>).</li> <li>○ Javier's parents value family and influences overall decision making (<i>familiso</i>).</li> <li>○ Javier's father identified socialization as 8/10 importance and is dissatisfied with Javier's engagement in social interaction (COMP).</li> <li>○ Mother appears to be the primary caretaker of Javier (<i>marianismo</i>).</li> </ul>	<ul style="list-style-type: none"> <li>○ Javier is diagnosed with ASD which impacts social participation in multiple contexts (<i>Principle 3 Family Systems Theory</i>).</li> <li>○ 14-year old male attending high school.</li> <li>○ Javier is a freshman at a new school that he is unfamiliar with.</li> <li>○ Javier is going through puberty.</li> <li>○ He is the oldest sibling (<i>Principle 7 of Family Systems Theory</i>).</li> </ul>

<b>Person Variables</b>		
<b>Sensorimotor</b>	<b>Cognitive</b>	<b>Psychosocial</b>
<ul style="list-style-type: none"> <li>○ Rocks himself back and forth when stressed - happens frequently during reading history material in class.</li> <li>○ “Shows an emotional or aggressive response to touch” (Dunn, 2014 p. 3) which inhibits participation in daily occupations (SP2).</li> <li>○ “Distress by changes in plans, routines, or expectations” (Dunn, 2014, p. 5), which inhibits transitions in unfamiliar contexts. (SP 2).</li> </ul>	<ul style="list-style-type: none"> <li>○ Javier has difficulty with organizing and planning future tasks which results in difficulty completing school tasks.</li> <li>○ Categorizes items based on preferences <ul style="list-style-type: none"> <li>■ Locker at school is organized by color and size.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ Javier perseverates on items he finds interesting (cars).</li> <li>○ Javier has limited social interactions skills which interferes with social participation with friends and family.</li> <li>○ Javier perseverates on his schedule and becomes agitated when routines change.</li> </ul>

## **Establish/Restore**

- **Social Skills**
  - Video Detective-Mother will video record Javier engaging in conversations with father and grandparents. Once video recording is complete, Javier and his therapist will watch the video without sound and have Javier identify emotions from his family members (Hilton, 2010).

## **Prevent**

- **Transitions**
  - Therapist and Javier will collaborate and identify songs that will assist him with transitioning in multiple environments.
    - One for school
    - One for home
    - One for ADLs
  - Once the songs have chosen transition times, Javier and the therapist will educate all family members and teachers on how to facilitate transitions with his selected songs.
  - This intervention will also reduce the goal of caregiver burden

## **Adapt/Modify**

- **School**
  - To increase his ability to pay attention in class and reduced stress, the therapist and Javier will explore fidgets that can be implemented in the class room. Therapist will also educate family members on the benefits of fidgets and have family explore fidgets that they can implement at home with Javier.

## **Alter**

- **School**
  - Due to Javier's difficulty with completing reading assignments in class, have Javier complete assigned readings at home with his

family. Make a sign-off sheet to ensure liability with school, family, and Javier

## **Create**

- **Social Participations/Family Cohesion**
  - Javier and his family will create a weekly game night. Each week a different family member will select the game. It is important to educate family members that Javier needs consistency and that family game night be repeated weekly. Have family report to therapist on interactions and areas they feel require more therapeutic services.

## **Case Scenario: Isabella - Level II Severity**

### **Occupation Based Assessment**

Using EHP to guide the assessment, the practitioner would begin by interviewing the family, Isabella, and Isabella's teachers (Dunn, 2017). Next, the practitioner would observe Isabella in a variety of contexts pertaining to Isabella and her family (Dunn, 2017). For Isabella, the assessments chosen included the Sensory Profile 2 (SP2) to gain an understanding of how her sensory patterns impact occupations. The Beach Center Family Quality of Life Scale (FQoL) administered to Isabella's caregivers (mother and grandmother) to gain an understanding of family interactions and how they influence occupational well-being. This assisted the occupational therapist in including family in the therapeutic process, as well as, provided a pre-and post-test measure for the effectiveness of family-based intervention. The last assessment used was the School Function Assessment to gain an understanding of Isabella's task performance and social interactions in the academic context (Coster, Deeney, Haltiwagner & Haley, 1998).

<b>Family &amp; Client Goals</b>
<ol style="list-style-type: none"><li>1. Increase family cohesion.</li><li>2. Increase family's knowledge of ASD.</li><li>3. Establish coping skill for Isabella to assist with emotional regulation.</li></ol>

Contexts			
Physical	Social	Cultural	Temporal
<ul style="list-style-type: none"> <li>○ Lives in an urban community.</li> <li>○ Isabella and her family live near her aunt, uncle and cousin (<i>familismo</i>).</li> <li>○ Attends school five days a week in a special education classroom.</li> </ul>	<ul style="list-style-type: none"> <li>○ Grandmother picks her and her two cousins up after school (<i>familismo</i>).</li> <li>○ Spends time around her family daily but how she interacts with them is limited.</li> </ul>	<ul style="list-style-type: none"> <li>○ Hispanic</li> <li>○ Lives with her mother and grandmother (<i>familismo, multigenerational home</i>).</li> <li>○ Isabella’s family chooses to live in close proximity to extended family (<i>familismo</i>).</li> <li>○ Religious view impact understanding of ASD (<i>Principle 8 of Family Systems Theory</i>).</li> <li>○ Mother and family are beginning to have a strained relationship (<i>Principle 6 of Family Systems Theory</i>).</li> <li>○ Isabella’s mother is dissatisfied with the support from her family (FQOL).</li> <li>○ Isabella’s sister is having to take a caretaker role as high importance is placed on family cohesion (<i>Principle 7 of Family Systems Theory</i>).</li> </ul>	<ul style="list-style-type: none"> <li>○ Isabella is an eight-year-old female.</li> <li>○ Isabella is in the second grade in a familiar classroom.</li> <li>○ Isabella is diagnosed with ASD which impacts her social participation in multiple contexts (<i>Principle 3 of Family Systems Theory</i>).</li> </ul>

<b>Person Variables</b>		
<b>Sensorimotor</b>	<b>Cognitive</b>	<b>Psychosocial</b>
<ul style="list-style-type: none"> <li>○ Uses words that provide sensory input to calm herself which can be disruptive to peers and family.</li> <li>○ Bites and scratches herself when she becomes overwhelmed, which impacts social relationships.</li> <li>○ “Rocks in chair, on floor, or while standing” (Dunn, 2014, p. 3). Isabella will often rock back and forth, as well as, pull on her ears when she becomes upset, which can result in self-harm behaviors (SP2).</li> <li>○ “Displays need to touch toys, surface, or textures” (Dunn, 2014, p3) which can be disruptive (SP2).</li> </ul>	<ul style="list-style-type: none"> <li>○ Difficulty with producing speech and typically uses intelligible words which interferes with social interaction.</li> <li>○ Perseverates on creating linear patterns and has intense need for order which result difficulty ADL tasks during her morning routine.</li> <li>○ Requires moderate assistance in setup and cleanup at school which impacts her participation of age appropriate tasks (SFA).</li> </ul>	<ul style="list-style-type: none"> <li>○ Rarely initiates social interaction with peers</li> <li>○ Has difficulty with emotional regulation which interferes with family and peer interactions.</li> <li>○ “Tunes me out or seems to ignore me” (Dunn, 2014, p.2), which impacts her relationship with her grandmother (SP2).</li> <li>○ Isabella requires extensive assistance in refraining from maladaptive behaviors which impacts her ability to participate in school (SFA). This also impacts how her family responds to her behaviors.</li> </ul>

## Establish/Restore

- **Social Skills**

- The therapist will provide Isabella and her family *The ZONES of Regulations* curriculum. This program is to foster emotional regulations (Kupers, 2011). The family should be included throughout the process. Examples of adapting family into a session is given below

- **Emotional Bingo (Lesson 2)**

- Warm-Up

- Have each family identify and demonstrate what emotion they are in today
- What color the emotions is categorized in

- Activity

- Each family member will have a BINGO card and BINGO pieces.
- Therapist will verbalize emotions, if Isabella or family member have emotions, they have to act it out and identify what color it is categorized in to put down a BINGO Piece

- Conclusion

- Have each member identify they favorite expression
- Have Isabella identify what new emotion she learned
- “How could reading someone’s facial expression change how you talk with that person?”



## **Prevent**

- **Family Cohesion**

- Therapist will request that multiple family members attend session if possible. Therapist will create a Jeopardy game on ASD. The whole family can participate and help each other with answers. Therapist will ensure that “just right” questions are implemented to increase self-efficacy with Isabella and her family. Therapist will also provide an educational brochure on ASD for each family member.

## **Adapt/Modify**

- **ADLs**

- Therapist will conduct a home visit to help modify the environment. The therapist will include both grandmother and mother as both participate in caregiver role. Mother, grandmother, and Isabella will modify bathroom and closet environment due to Isabella’s preference for order and organization. Modifying these environments will help Isabella and her family’s participation with daily routines.

## **Alter**

- **Community Integration**

- The family enjoys grocery shopping and cooking due their culture. However, they find it difficult to include Isabella. Therapist suggest altering the environment by changing what grocery store they shop at. Isabella is over stimulated with large grocery stores and changing to a smaller grocery store with minimal environmental stimuli may help with Isabella’s maladaptive behaviors. As Isabella established emotional regulation, it is possible to return back to a larger grocery store

## Create

- **Sensory/Relaxation Room**
  - Due to high stress in the household, the therapist encourage family to create a relaxation area within the home (calm music, variety of texture, low lighting, etc.). Educate family members on purpose of relaxation room, need for coping tools, and how family can participate in this activity together to increase family cohesion.

## **Case Scenario: Theresa - Level III Severity**

### **Occupation Based Assessment**

Using EHP to guide the assessment, the practitioner would begin by interviewing Theresa's family and daycare providers (Dunn, 2017). Next, the practitioner would observe Theresa in a variety of contexts pertaining to Theresa and her family (Dunn, 2017). For Theresa, the assessments chosen included the Sensory Profile 2 (SP2) to gain an understanding of how her sensory patterns impact occupations. The Parent Sense of Competence Scale was also used to evaluate the mother and grandmother's competency in their familial role. This allowed the occupational therapist to gain an understanding on how to increase family cohesion and overall understanding of Theresa's needs. The last assessment utilized was the Bruininks-Osertysky Test of Motor Proficiency (BOT-2). This assessment was used to measure Theresa's motor skills through engagement in activities (Bruininks & Bruininks, 2005).

### **Family & Client Goals**

1. Increase Theresa's ability to regulate her emotions.
2. Increase Theresa's social participation.
3. Establish coping skills within the family to increase family cohesion.
4. Increase extended family's knowledge of ASD.

Contexts			
Physical	Social	Cultural	Temporal
<ul style="list-style-type: none"> <li>○ Lives in a rural community with little diversity.</li> <li>○ Enrolled in a local daycare that is new and unfamiliar.</li> <li>○ Theresa lives in a five-bedroom home.</li> <li>○ Theresa's has difficulty with bilateral coordination (BOT-2).</li> </ul>	<ul style="list-style-type: none"> <li>○ Isolates herself at daycare and won't play with others.</li> <li>○ Theresa doesn't have any siblings but has older female cousins.</li> <li>○ Theresa's grandmother takes out her frustration on Theresa (<b>Principle 4 of Family Systems Theory</b>).</li> <li>○ Theresa's mother avoids conflict with her mother and sisters (<b>simpatía</b>).</li> <li>○ Theresa does not properly respond to her grandmother (<b>refrains and dichos</b>).</li> <li>○ Theresa's mother reports a lower sense of competency in her role as a mother, whereas Theresa's grandmother reports a higher sense of competency in the role of parenting (PSOC)</li> </ul>	<ul style="list-style-type: none"> <li>○ Hispanic</li> <li>○ Family places high value on respecting elders (<b>respecto</b>).</li> <li>○ Lives with her mother, father, grandmother, aunt and female cousin (<b>familismo, multigenerational home</b>).</li> <li>○ Grandmother has a strained relationship with Theresa (<b>Principle 6 of Family Systems Theory</b>) (<b>obediencia</b>).</li> </ul>	<ul style="list-style-type: none"> <li>○ Theresa is a five-year-old female.</li> <li>○ Theresa attends daycare three times a week.</li> <li>○ Theresa is diagnosed with ASD which impacts her behavior and communication (<b>Principle 3 of Family Systems Theory</b>).</li> <li>○ Grandmother is having a difficult time accepting diagnosis (<b>fatalismo, respeto</b>) (<b>Principle 2 of Family Systems Theory</b>).</li> </ul>

<b>Person Variables</b>		
<b>Sensorimotor</b>	<b>Cognitive</b>	<b>Psychosocial</b>
<ul style="list-style-type: none"> <li>○ Theresa’s auditory and visual defensiveness interferes with family and peer interactions.</li> <li>○ When Theresa becomes upset, she is not able to regulate her emotions which often results in her hiding in tight spaces or eloping.</li> </ul>	<ul style="list-style-type: none"> <li>○ Theresa uses sign language or hand gestures to communicate with her family.</li> <li>○ Theresa’s interests and repetitive behaviors interfere with her ability to terminate activities at home and daycare.</li> </ul>	<ul style="list-style-type: none"> <li>○ Theresa does not have age appropriate social skills which prohibits her from engaging with her peers and results in isolative play.</li> <li>○ Theresa is unable to interpret family norms and expressive communication which leads to tension amongst family members.</li> <li>○ Theresa frequently has temper tantrums that impact Theresa’s ability to complete occupations. This also impacts how Theresa’s family responds and understands her behaviors (SP 2).</li> <li>○ Theresa “resists eye contact” with family members which impacts family cohesion (SP 2).</li> </ul>

## Establish/Restore

- **Social Skills**

- The therapist will provide Theresa and her family *The ZONES of Regulations* curriculum. This program is to foster emotional regulations (Kupers, 2011). The family should be included throughout the process. Examples of adapting family into a session is given below

- **Creating Wall Posters of the Zones (Lesson 1)**

- Warm-Up

- Ask family members what common saying they utilize in the home.
- Educate the family on the zones and what they entail.

- Activity

- Each family member will create a poster for the designated Zone.
- Therapist will include certified translator in this session. The therapist, translator, Theresa and family will translate emotions into Spanish terms to increase communication within the family. Grandmother has expressed frustration due to lack of communication and “respect” with Theresa. Having the charts at home, Theresa can point to emotions or responses she wants to communicate with her family members.

- Conclusion

- Have each member act out an emotion in each zone.
- Have Isabella identify what new emotion she learned
- Ask “Why is it important to understand other people’s emotions?”

## **Prevent**

- **Family Cohesion**
  - Therapist will create a stress management Jenga game. Each Jenga piece will correlate to a scenario, stress management technique, and/or coping skills. Family members will practice coping skills or role play scenarios that they pull. This game is intended to prevent family miscommunication and stress.

## **Adapt/Modify**

- **Emotional Regulation**
  - Due to self-harm behaviors, Therapist will explore fidget options with Theresa and family to use at home and at school. Therapist will then educate day care provider and family on how to utilize selected fidgets in the school and home environment to reduce maladaptive behaviors as a result of decreased emotional regulation.

## **Alter**

- **Community Integration**
  - Therapist will suggest exploring other day care options that are a better fit for Theresa and her needs. Aspects in a day care to meet Theresa's needs may include
    - 1:1 teacher/child ratio
    - Mentor
    - Sensory gym
    - Minimal peers
    - Day care providers educated on ASD
    - Structured day care programs

## Create

- **Sensory/Relaxation Room**

- Therapist will advocate to day care provider on creating a sensory corner or room, whichever is more feasible, for emotional regulation and sensory exploration. Therapist will educate day care provider on benefits of sensory exploration and emotional regulation in all children. This will assist in helping Theresa's feel included in the day care setting and practice regulating her own emotions with her peers.



# Resources

Literature has identified that families report lack of resources and support networks to navigate through their child's diagnosis of ASD. (CITE). Below is a list of resources that therapist can utilize during the therapeutic process with the child and family. The resources below are also resources that the therapist can recommend for families to assist with navigating through their child ASD diagnosis. Resources vary between communities and it is encouraged that the therapist look at resources available in the given community they are practicing in and where the family resides.

## Books

- Melmed, R. & Wheeler, M. (2015). *Autism and the extended family: A guide for those outside of the immediate family who know and love someone with autism*. Arlington, TX: Future Horizons Inc.
- Meloy, C.G. (2013). *Life & spectrum*. Canada: Creative Combinations LLC.
- Kuhaneck, H.M. & Watling, R. (Eds.). (2010). *Autism: A comprehensive occupational therapy approach* (3rd ed). Bethesda, MD: American Occupational Therapy Association Inc.

## Websites

The Autism Speaks organization is an informational website that provides family, practitioners, and individuals with valuable information on the diagnosis.

- <https://www.autismspeaks.org/>
- When exploring the website above, one can navigate through the tabs to identify multiple resources. The list below are examples of identified resources on the website. The list below provides minimal examples and a therapist should navigate through the website to increase overall knowledge and resources for ASD.
  - What is Autism?

- <https://www.autismspeaks.org/what-autism>
- Resources by life stage
  - <https://www.autismspeaks.org/directory>
- Treatment Options
  - <https://www.autismspeaks.org/treatments>
- Advocacy
  - <https://www.autismspeaks.org/advocate>
- Insurance
  - <https://www.autismspeaks.org/health-insurance-coverage-autism>

#### The National Autism Resources

- <https://www.nationalautismresources.com/>

#### National Autism Center

- <http://www.nationalautismcenter.org/resources/for-families/>

#### Autism Resources Center

- [https://www.aacap.org/aacap/Families\\_and\\_Youth/Resource\\_Centers/Autism\\_Resource\\_Center/Home.aspx](https://www.aacap.org/aacap/Families_and_Youth/Resource_Centers/Autism_Resource_Center/Home.aspx)

#### Autism Society

- <http://www.autism-society.org/>

#### Autism Action Partnership

- <https://autismaction.org/resource-center/helpful-websites/state-and-federal-government-resources/>

#### National Hispanic Institute (NHI)

- <https://www.nationalhispanicinstitute.org/>

#### National Hispanic Medical Association

- <https://www.nhmamd.org/>

### Latino/a/x Resources

- <https://namica.org/representrecovery/latino-resources/>

### The Committee for Hispanic Families and Children (CHFC)

- <https://www.chcfinc.org/>

### Latino Health Resource Guide

- <https://www.medicareadvantage.com/latino-health-resource-guide>

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- Beach Center on Disability. (2012). The family quality of life scale (FQOL). Measurement Instrument Database for the Social Science. Retrieved from [www.midss.org](http://www.midss.org)
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## CHAPTER V

### Summary

#### Overview

The purpose of this scholarly project, *Toda La Familia: An Occupational Therapy Resource Guide for Working with Latino Children Diagnosed with ASD and Their Families*, was to create a resource manual for occupational therapists working with Latino children diagnosed with ASD and their families. More specifically, the resource guide was created to increase occupational therapists' knowledge on how to implement culturally appropriate and family-centered care when working with Latino families and their child diagnosed with ASD. It was important for the developers to incorporate a collectivist perspective, as the literature identified that Latinos value *familismo* (Fallon & Quintana, 2015).

The literature review in Chapter II indicated the need for culturally appropriate interventions for Latino children diagnosed with ASD and their families. The literature suggests that interventions that are culturally appropriate improve outcomes and promote family-centered care. However, most evidence-interventions were researched on mid-upper class, White, English speaking children. Occupational therapists are equipped to address cultural and familial values and beliefs, as well as addressing different contexts, therefore they would be a beneficial skilled service in this context.

The product was developed to promote occupational therapists' knowledge of

Latino culture, providing services that incorporated culture, and decrease bias when working with this ethnic minority group. A critical component of the resource guide was the integration of family and was the foundation for the authors selecting Family Systems Theory (FST) and Ecology of Human Performance (EHP).

The product was broken down into sections that were of most importance when working with Latino families. This includes relevant terminology, family-centered care, autism spectrum disorder, culture, theory, evaluation, interventions, clinical application, and resources. Each section contains information to help guide the therapist, as well as aid them in becoming a more culturally competent practitioner. Each section focuses on the integration of the family into the therapeutic process.

### **Limitations**

There are limitations that exist within this guide. The first limitation of the product is the lack of culturally centered, evidence-based interventions. The developers provided occupational therapists with a list of evidence-based interventions and approaches to guide family centered and culturally sensitive care. However, due to the lack of research for ASD interventions that consider minority groups, the proposed interventions are evidence based and researched on White, mid to upper class, English speaking children. Interventions were based on the existing literature and therefore must be adapted to the specific client and their culture, which could impact the validity and reliability of the intervention.

The second limitation is that the guide lacks assessment tools that consider environments for children diagnosed with ASD. Although there are present examples of evaluation tools to use to address different contexts, there are no assessments that

specifically target the child's environment. This limits the opportunity for the occupational therapist to thoroughly consider the child's changing environments and consider how this impacts behaviors.

The third limitation of the product is funding and reimbursement. Funding and reimbursement are influenced by insurance companies and facilities. The culturally adapted intervention examples provided by the developers were based off of previous evidence-based literature. However, the specific interventions may not be considered evidence-based due to the developers adapting the inventions to fit the Latino culture. Therefore, insurance companies may not reimburse the intervention as identified by the examples provided by the developers and a facility may not provide the resources to implement proposed interventions.

### **Recommendations**

Two primary recommendations for the product are that it be piloted in practice and that future research be conducted on culturally appropriate interventions for Latino children diagnosed with ASD. This project has yet to be implemented in practice or used by licensed and registered occupational therapists which decreased the validity of the product.

The first recommendation for future use of this product is to include a pilot implementation of the resource guide in practice. This will assist the developers in determining if the product is feasible and what aspects of the product produces satisfactory results in Latino children diagnosed with ASD and their families. The second recommendation is that research be conducted on culturally appropriate interventions for Latino children diagnosed with ASD. This project has yet to be implemented in practice

or used by licensed and registered occupational therapists. A pilot implementation of the resource guide in practice would be beneficial for feedback, accuracy, and recommended changes. The goal of the resource manual is for occupational therapists working with this population to become more culturally sensitive and family-centered. Therefore, feedback from licensed and registered therapists would be of advantage for the developers to make alterations for improved accuracy.

The final recommendation is for research to be conducted on both evidence-based and culturally appropriate interventions for Latino children diagnosed with ASD. Due to the lack of literature supporting interventions designed specifically for this population, it is necessary that this research be implemented in the near future. This type of research would fill the gap in literature and help the profession of occupational therapy grow.

### **Implementation**

In the future, the developers foresee this product being implemented in inpatient, outpatient, community, and school-based practice areas. This manual has the potential to be incorporated into the therapeutic process and aid therapists in becoming more culturally sensitive and family-centered. While this manual was created specifically for Latino families and their child diagnosed with ASD, the overarching concepts could be applied to other minority groups. The manual offers information on family-centered care, evaluation tools, and theory that could easily be applied to other minority groups. Additionally, the information provided within the resource guide plants a seed for therapists to begin thinking about how they approach families and their own biases.

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