

EVALUATION OF FAMILY FUNCTIONING FOLLOWING PARENT  
PARTICIPATION IN RECREATIONAL INTERVENTION FOR CHILDREN  
WITH AUTISM

DISSERTATION SUBMITTED TO THE FACULTY OF  
THE ADLER SCHOOL OF PROFESSIONAL PSYCHOLOGY

BY

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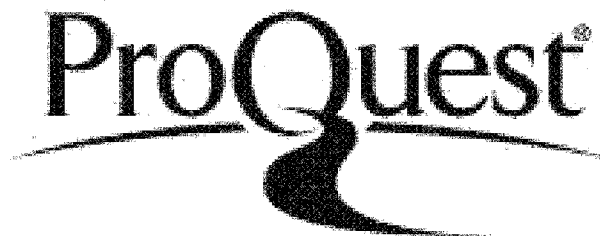


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### Abstract

The purpose of this study was to better understand the parenting experience Latino parents of children with autism before and after participating in an 8-week family recreational pilot intervention program which was facilitated by behavior therapists and framed using Nintendo's Wii gaming console. Archival data from this pilot program was utilized to assess the impact of the intervention. The sample consisted of eleven parents with a child between the ages of five and nine who had been diagnosed with an autism spectrum disorder and at least one neurotypical sibling. Families were all enrolled from a greater sample of a university based developmental clinic and its associated family support group. Parental perception of family impairment, parental sense competence, and maladaptive behaviors were measured at pre and post intervention using the Family Life Impairment Scale, The Parental Sense of Competence Scale, and the Vineland-II Adaptive Behavior Scales Spanish/English Caregiver report Version II. Following participation in the program, parents reported significant increases in parental competency but no statistically significant differences were found in family impairment. No correlations were found between maladaptive behaviors and measures of family functioning. A comparison between families where one parent participated and those where two participated found that when two parents participated, families experienced higher levels of impairment.

Dedication

This dissertation is dedicated to the memory of  
Elina R. Manghi, Psy D, LMFT

To my mentor,  
my advisor,  
my teacher,  
my role model,  
my hero,  
my friend,

You were everything I always wanted to be,  
and you taught me what I know today.

I can't wait to see what  
"We're going to do next!"

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I am first and foremost grateful to God for encouraging my faith in myself as I developed my faith in Him, for the obstacles and challenges that taught me how to climb over and soar, for my family with its genetic mix of blessings and quirks, and simply for allowing me to be.

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I am grateful and inspired by the many mental health professionals who have guided me personally and professionally. To my committee, Dr. Cox, Dr. Alvarez, and Dr. Dyson, thank you for your patience, feedback, and encouragement. This work could not have existed without the support, knowledge, humor, and intellectual curiosity of one of my original committee members and former chair, Dr. Elina Manghi. I am forever grateful to have known you, been inspired by you and learned from you. To Dr. David Kaiser, my

therapist, thank you for helping me understand, forgive, believe, and accept; for asking difficult questions, holding me accountable, and helping me see not only the life I could have, but the life before me. You have changed my life. A BIG thank you to “my girls” and study-buddies, you soon-to-be psychologists, for making me laugh, lifting me up when things got hard, for inspiring me and simply for being my friends.

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Last but certainly not least, to my parents, Jose Luis & Martha Elena Gonzalez – gracias por siempre creer en mi y apoyarme a cada paso. Your lives have not been easy but you've worked so hard and sacrificed to give me the best of everything, most importantly education –at home and at school. Watching you, I learned that hard work has great results, education opens doors and minds, and that our experiences make us stronger. You taught me to work and your faith in me has lifted me up and over each obstacle. Ever since I was little, you've shown me through your love, support, and your incredible examples, that I could truly do anything. I want you to know, of all the things, I've done and all the things I am, the one that I am most proud of is simply being your daughter.

Martha Citlaly Gonzalez



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## **Chapter I**

### **Introduction**

Awareness of autism spectrum disorders across research, clinical, and the general community is growing as prevalence rates continue to rise. However, much of the existing research, resources, and services available to the public are focused primarily on children's symptomatology, seldom incorporating the family into treatment. Information on etiology, symptoms, prevalence, and treatment is undeniably important, but understanding how having a child with autism affects family functioning is arguably as critical, given that the family forms the primary social circle and children depend on their parents to access services.

Autism Spectrum Disorders (ASD), hereto referred as autism, are one of the most common forms of developmental disabilities (Boyd, Odom, Humphreys, & Sam, 2010). The latest prevalence rates estimate that one in sixty-eight children and one in forty-four boys meet criteria for autism spectrum disorder (Centers for Disease Control and Prevention, 2014). Since Kanner published the first clinical report on autism in 1943, the approach to how autism is defined, conceptualized, diagnosed, and treated has undergone various changes. The DSM-V currently defines autism spectrum disorders as an umbrella term for neurodevelopmental disorders characterized by qualitative impairments in three domains, including social interaction, communication, and the presence of restricted interests or

repetitive or stereotyped behaviors. These impairments occur within the first three years of life and persist throughout the lifespan, affecting not just the individual, but those around them, including and especially family and caregivers (American Psychiatric Association, 2013).

Despite autism's growing rates and prevalence across all ethnic groups, few studies have explored how autism spectrum disorders are conceptualized across cultures (Welterlin & LaRue, 2007). This gap in knowledge creates barriers and may not only interfere with the delivery of culturally appropriate interventions but may also deter immigrants from interacting with health systems. One particularly troublesome effect of systemic barriers has resulted in disproportionate growth rates and significant delays in diagnosis for Latino children, which may not reflect a true difference in prevalence, but gaps in diagnostic procedures (Centers for Disease Control and Prevention, 2014; Fombonne, 2003)

The Latino population in the United States, which refers to people who originate from Latin America, including Central and South America, grew 43% between 2000 and 2010 accounting for 56% of the nation's growth (U.S Census Bureau, 2012). To address the needs of the fastest growing segment of the U.S. population there is an ever-increasing need for practitioners, legislators, and researchers to deduce how Latinos access and navigate systems, especially health care. Latino parents of children with autism have reported difficulties interacting



with systems based on finances, lack of information, and language (Sanchez, 2006). The result is a set of barriers to educational, behavioral, and health care systems which negatively affect family functioning within a group already battling a number of stressors related to their children's condition (Welterlin & LaRue, 2007).

Numerous studies have demonstrated the relationship between elevated stress and declines in perceived family functioning. Those who have difficulty parenting are also more prone to experience low self-confidence, low self-esteem, and impaired well-being (Higgins, Bailey, & Pearce, 2005). On the other hand, parenting self-efficacy and parenting competence, two concepts that are heavily intertwined within the literature, are associated with positive developmental outcomes in children. Parents who face additional demands and hardships associated with autism may have fewer experiences of parenting success and thus feel less efficacious in their role as parents. Unfortunately, this contributes to more problems as low parental efficacy is related to increased incidence of child behavior problems (Hastings & Brown, 2002).

Parents of children with autism tend to experience higher than average levels of stress, poorer quality of marriage, rates of mood disorders, and poorer family functioning than families of typically developing children (Davis & Carter, 2008; Kuhlthau et al., 2010; Magaña & Smith, 2006; Rao & Beidel 2009; Schertz & Odom, 2007). Even when compared to parents of children with other

disabilities, parents of children with autism experience higher levels of stress, poorer health, and a greater negative impact related to the child's disability (Hastings et al., 2005; Smith et al., 2010). Poor family functioning is cause for concern not only because of the deleterious effects of stress on parents but because of the associated effects on child development, especially salient for children diagnosed with a developmental disability. Research has shown that stress and low self-esteem are linked to decreased engagement with health services, less than optimal parenting, poorer outcomes after interventions, and impeded child development (O'Connor, 2002).

Several factors contribute to the parental stress experienced by parents of children with autism, including the search for appropriate services, the frustrations of having to navigate systems, and the day-to-day challenges of parenting a child with a disability. Behavioral problems and poor adaptive functioning in the children are the best predictors of, and are correlated with, higher levels of parental stress and need for family support (Boyd, 2002; Gray, 2002; Rezendes & Scarpa, 2011). Overwhelmingly, research has shown that parents whose children exhibit a high degree of maladaptive behavior tend to experience poorer levels of subjective health. The relationship between behavior and well-being is an important factor to consider when examining family functioning and parental competence, as the stress negatively affects the parents' ability to engage in treatment.

Traditionally, evidence-based treatment models have focused on skill-building, targeting the core areas of deficits associated with autism. The most commonly used evidence-based treatment models are grounded in behavior therapy (National Research Council, 2001). Treatment, regardless of modality, should include treatment plans modified to address the individual child's needs, strengths, and weaknesses. In addition to child engagement in any of these and other interventions, parents frequently participate in psycho-education programs focused on diagnosis and treatment while also providing support to parents of children with autism.

Treatment programs have recognized the positive effects of including the family in treatment (Altiere & Kluge, 2009). Attending to parent child relationship and perceived success within the parenting experience is crucial since quality relationships are related to higher levels of optimism and increases in perceived well-being for parents (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Furthermore, inclusion of the family in treatment allows for parents to practice learned skills to promote positive behavior and family cohesion.

### **Statement of the Problem**

The stressors that exist when rearing a child with a disability are undeniable. However, when a family remains stressed, family functioning is likely to suffer. However, teaching valuable skills to the entire family and

practicing them as a group within an enjoyable recreational activity encourages family interaction and ultimately may help improve family functioning.

Past research has shown that families of children with developmental disabilities tend to participate less in family interactions and recreational activities than families of neurotypical children. This finding is troubling given that research has also shown that family recreation positively contributes to family cohesion, marital satisfaction, and social functioning all of which may also serve as protective factors guarding against negative effects of stress (Mactavish & Schleien, 2000). Beyond the positive implications for family functioning, family recreation activities aid in promoting healthy child development and integrating children with developmental disabilities into community recreation (Mactavish & Schleien, 2000).

A review of the literature found no existing programs similar to the current investigation or pilot intervention program. Although there were various examples of interventions aimed at reducing stress, examining family functioning, and the benefits of participating in recreational activities, none combined the three factors in a family intervention. Moreover, much of the literature on autism has focused on child factors, not on parenting experiences. Clinicians have used video games in interventions for children with autism, but thus far the focus has been on motor development not social development or family functioning (Griffiths, 2003). Two exceptions include a study that used video games in conjunction with behavior

skills training to teach sportsmanship skills and a widely cited anecdotal account of a child whose video game play helped him develop language, academic and social skills (Demarest, 2000; Ferguson, Gillos, & Sevlever 2013). However, though the latter included parental participation, it was not a scientific study and did not examine the effects on family functioning. Nevertheless, it sparked discussion in academic journals and served as a model for intervention for the scientific community.

### **Statement of Purpose**

This study focuses on the experience of Latino parents of children with autism, their level of family functioning, parental competency, and how children's maladaptive behaviors influence both. The researcher used archival data collected for a pilot program facilitated at a Midwestern university. Participants for this program were drawn from a family support group for Latino parents of children with autism. Parents participated in a family recreation intervention facilitated by a behavior therapist using Nintendo's Wii as a framework for family recreation and behavior skills training. The goal was not only to develop the children's skills but to include the family in treatment and teach parents to promote pro-social behavior during a fun family activity with the hopes of enriching family functioning. Researchers chose to use a gaming console in response to the popularity of video games since these have long dominated the toy industry and have become a driving social force that shapes children's play and

lifestyles. A 2008 study found 97% of adolescents reported having played video games with half of the respondents reporting regular play. Despite the large number of children involved in video game play, only a small percentage of parents regularly played with their children while close to half reported that they never played video games with their children (Lenhart et al., 2008).

For families with children with autism who experience limitations in recreational opportunities and whose children are especially drawn to video games, this area represents a key area for research and interventions geared to positive family functioning. It is the researcher's hope that this information will be useful to clinicians working to strengthen the family bonds of this vulnerable group.

### **Assumptions and Limitations**

Based on the literature, it is assumed that families of children with autism experience elevated stress which negatively affects parenting competence and perceptions of family functioning. The researcher assumed that the measures used reliably assessed the aforementioned factors based on the psychometric properties of each of the measures selected. It was also assumed that an intervention based on behavior therapy would be effective at changing not only child behaviors but parent perceptions. Most current evidence-based interventions are based in behavior theory including parent psycho-education but a review of the literature revealed few studies where the family was incorporated in treatment. This study

was limited by various factors including the sampling pool for the archival data, which was comprised of parents who self-selected to participate in a family support group and who, therefore, may have been more motivated to engage in treatment. Additionally, these families may have initially experienced more positive family functioning when compared to other families with children with autism as a result of their membership in a support group. Another limiting factor is the small sample size. However, as this study utilized data from a pilot program, it is hoped the information yielded by this study will help to inform and stimulate future interventions and treatment.

### **Research Questions**

This study examined archival data to assess the impact of parental participation in a recreational pilot intervention program, which was designed to promote pro-social behavior and self-control in children while encouraging a positive family interaction. The research question studied was if this program participation resulted in positive effects on parental perceptions and family functioning. Research evaluating the effect of this program on family functioning will contribute to the current understanding and how to better address their needs. This study will address the following research questions:

1. Did participation in this pilot program result in higher parental self-efficacy and parental competence?
2. Did participation in this program result in improved family functioning?

3. Were there any relationships between children's maladaptive behaviors, parental sense of competence, and family functioning?
4. Were there any differences at the end of the intervention between family groups where one parent participated versus two on any measure of family functioning (parental competence and family impairment)?



## **Chapter II**

### **Review of Literature**

The conceptualization of autism, from diagnosis to treatment and the factors that inform each of these, helps to establish treatment decisions for children and their families. This literature review will give a brief description of autism spectrum disorders, describe how they contribute to heightened stress in families, and examine how perceptions of stress, family functioning and parental competence affect parent emotion, child development and treatment outcomes. This information is then applied to better understand how parents of children with autism experience and cope with stress.

Though previous literature has confirmed the heightened levels of stress experienced by families of children with autism, few researchers have explored how family recreation may help reduce parental stress and increase family cohesion. Fewer still have examined these variables in Latino populations. This review covers empirical studies, meta-analyses, theoretical article and case studies to build an understanding of family functioning and provide the basis for studying and evaluating the effects of the pilot intervention program. Using this information, the researcher sought to examine whether a program which combines recreation and video games with behavioral interventions promotes positive family functioning in Latino families with children with autism.

## **Etiology, Prevalence, and Diagnosis**

Autistic Spectrum Disorders encompass a category of neurodevelopmental disorders characterized by impairments in three areas including communication, social skills, and the presence of restricted interests and unusual or repetitive behaviors (American Psychiatric Association, 2013). These symptoms may manifest themselves in a number of ways and to varying degrees. For instance, deficits in communication may range from being completely non-verbal, using augmentative communication systems, or even children who can communicate verbally, but who may have challenges with pragmatic language and use of gestures. Intonation, volume, and cadence may also be affected. Social skills deficits may include impaired ability to initiate, reciprocate, and maintain social interactions, reduced joint attention, and limited insight into social situations. Children with autism tend to have difficulty with pretend skills, imaginary play, imitation and social skills including turn taking (Lord et al., 2000). While all individuals with autism will have deficits in the above areas, the patterns, severity, and levels of functioning will manifest differently from individual to individual and affects all areas of functioning persisting throughout the life-span.

Autism is diagnosed on the basis of comprehensive interviews, observations, and a battery of tests that may include screening instruments such as the Gilliam Autism Rating Scale and the Asperger Syndrome Diagnostic Scale,

interview based measures such as the Vineland-II and the Autism Diagnostic Interview-Revised (ADI-R), and observation-based instruments such as the Childhood Autism Rating Scale and the Autism Diagnostic Observation Schedule –II (Lantz, 2003). Considered the gold-standard for autism assessment and administered only by certified clinicians, the ADOS-II is a semi-structured assessment of communication, social interaction, play, and repetitive behaviors or stereotyped mannerisms. Behaviors are observed, rated, and then calculated using an algorithm with thresholds for each section. Though not used as a definitively diagnostic instrument, the ADOS-II classifies children into those whose performance is within the range of children with autism (De Bildt et al., 2004; Lord, Rutter, DiLavore, & Risi, 2008). The literature cited within this review included only studies in which the children were diagnosed using the ADOS-II, ADI-R, and DSM criteria in their latest versions at the time of publication with few exceptions.

The past decade has seen an explosion of information and awareness of autism. However, despite rising prevalence rates and more access to information, the etiology is still not definitively known. In recent years, the rates of diagnosis have increased dramatically. Most recent statistics indicate that autism spectrum disorders occur in one out of 68 individuals. More prevalent in boys, autism occurs at rates of one out of 42 for males and one out of 189 for females (Centers for Disease Control and Prevention, 2014). Though diagnosed less frequently,

girls experience higher symptom severity and are more likely to have lower intelligence quotients (Rice, 2007). There is some debate about whether the rise in prevalence reflects a true growth, increased awareness, or more sensitive diagnostic tools. One possible explanation is that because autism is now understood to be a spectrum disorder, children are being diagnosed who may not have been in the past (Boyd et al., 2010; National Research Council 2001).

Autism spectrum disorders occur across racial, ethnic, and socioeconomic classes with no difference in prevalence existing between ethnic groups (Boyd et al., 2010; Fombonne, 2003). Despite the increase in prevalence, Latino children are being diagnosed at lowered rates (Mandell et al., 2009). Lowered prevalence rates of autism in Latinos do not reflect a smaller incidence of autism, but a pattern of under and misdiagnoses brought by socio-cultural factors including social and economic differences, language barriers, and mistrust in the medical community among other variables (Mandell et al., 2009). Failure to identify children has serious implications on eligibility for appropriate treatment, prognosis, and family functioning.

### **Stress and the Parenting Experience**

There is no question that raising a child with autism is a challenging experience and that parents of children with autism experience greater stress and poorer family functioning than other parents (Davis & Carter, 2008; Gray, 2002;

Hastings et al, 2005; Kuhlthau et al., 2010; Myers, Mackintosh, & Goin-Kochel, 2009; National Research Council, 2001; Osborne, McHugh, Saunders, & Reed, 2008; Phelps, McCammon, Wuensch & Golden, 2009; Rao & Beidel, 2009; Rodrigue, Morgan, Geffken, 1990; Shur-Fen Gau et al., 2012; Smith et al., 2010; Sivberg, 2002). Along with heightened stress, parents of children with autism tend to experience more arguments, fatigue, and symptoms of depression (Smith et al., 2010). It is necessary to examine the factors that contribute to stress, especially those related to culture, family functioning, parental competency in order to improve family functioning, reduce parental stress, and promote healthy family interactions.

Parental stress is not limited to the challenges related to the child-rearing experience but may also result from the complexities associated with navigating multiple systems to procure treatment. For minority families, the need to do this in their non-native language and in a country whose laws and policies are foreign to them, the task may seem even more daunting. Accessing services, therefore, may result in feelings of frustration, misunderstanding, and dissatisfaction, especially related to the language barrier, resulting in higher levels of attrition from health care services by Latino families (Ngui & Flores, 2006). Other significant sources of stress include the permanency of the disorder, alienation from family members and society, and lack of professional support (Sharpley, Bitsika, Efremidis, 1997).

In a large scale qualitative study of parental perceptions on raising a child with autism, 24 themes then subsumed into five clusters emerged: stress; child's behavior; parental well-being work, marital relationship; impact on the whole family and social isolation, congruent with the themes found in this review (Myers et al., 2009). Although this study focuses on parents' experience, a bidirectional relationship exists through which both parents and children are affected by the emotional, behavioral, and social factors related to autism.

Rearing a child with a disability requires parents to take on many roles. According to Stoner and Angell, there are four main roles including that of negotiator, monitor, supporter, and advocate (2006). These tasks encompass the need to negotiate for services, monitor the quality of education, encourage and assist their children and those who work with them, and advocate in activities that will help their children and those who are affected by similar conditions. Though participation in these tasks is ongoing, specific responsibilities and degree of involvement change over time. The period following diagnosis, typically in early childhood, marks one of the most intensely stressful times for parents as they struggle to figure out how to procure an accurate diagnosis and access appropriate services. Over the next years parental focus shifts to managing educational placement, fostering adaptive skills and promoting independent functioning. However, time and energy spent on any and all of these activities leaves less time allotted for parents to engage in personal and leisure activities (Smith et al., 2010).

Limited time to spend in leisure activities and personal interests is one result of the time spent engaged on care-taking duties. Delays in communication and social skills are quoted by parents as two of the most important areas of development and are often what leads parents to seek help from professionals (Davis & Carter, 2008). However, the literature overwhelmingly suggested behavioral symptoms are the primary source of parenting stress and a key contributor to poor family functioning (Hastings et al., 20005; Levac, McCay, Merka, & Reddon-D'Arcy, 2008; Phetrasuwan & Shandor Miles, 2009; Rao & Beidel, 2009; Rezendes & Scarpa, 2011). The combination of externalizing behaviors and decreased family functioning are significant contributors to increased negativity in parenting perceptions and social functioning (Sikora et al., 2013).

Behavior problems often occur as a direct result of the challenges stemming from the core deficits associated with autism. For instance, self-injurious behaviors may help the child self-regulate; aggression may occur because of difficulties with communication, and obsessive-compulsive behaviors may be a manifestation of the rigidity that many children with autism exhibit. These behaviors may lead parents to experience isolation, anxiety, stress, and depression and challenge the parent-child relationship (Greenberg et al., 2004). Reports of a lower rate of behavior problems in children with other disabilities may explain why parents of children with autism report higher levels of stress than parents of

children with other disabilities (Boyd, 2002; Gray, 2002; Hastings et al., 2005). One study found maladaptive behavior problems accounted for 32% of the variance in maternal stress that led to depression (Tomanik, Harris, & Hawkins, 2004). In fact, problem behaviors and poor adaptive functioning have been found to be the best predictors of parental stress (Boyd, 2002; Gray, 2002; Rezendes & Scarpa, 2011). While prolonged exposure has stronger negative effects on the families, researchers have also found that as the child grows older behavioral problems tend to decrease and with these, parental stress levels (Gray, 2002).

Much of the literature focused on the experiences of mothers as most often, the responsibility to seek diagnoses, interventions, and attend treatment falls to them (Gray, 2003; Sivberg, 2002). In part because of child-rearing responsibilities, fewer mothers than fathers tend to report being able to work outside of the home. Unsurprisingly, mothers tend to experience higher levels of stress, more depression symptoms, and perceive family functioning more negatively compared to fathers (Gray, 2002; Hastings et al., 2005). One of the reasons may experience stress differently from mothers is that not only do they typically handle less of the care-taking duties, but fathers tend to use avoidance as one of the chief coping mechanisms used to minimize stress and they tend to find more of their personal meaning from their work outside the home (Bristol, Gallagher, & Holt, 1993; Gray, 2003; Hastings et al., 2005). Avoidance is a problematic coping strategy given its limited usefulness in the long term, its



associations with increased stress and mental health problems, and the fact that it does not let one practice skills or build a repertoire of more positive experiences (Hastings et al., 2005). Furthermore, engaging in avoidance techniques leaves the other parent with increased responsibility and lends itself to placing blame on the mother when things do not go well (Gray 2003). Systematic analyses of psychological functioning in families of children with autism found that while maternal stress is predicted by child behavior problems as well as their partner's anxiety, paternal stress is more influenced by maternal depression and low rates of positive perceptions (Hastings et al, 2005).

Parents of children with disabilities report high levels of marital stress and poor marital satisfaction (Hastings et al., 2005; Higgins et al., 2005; Rodrigue, Morgan, & Geffken, 1990; Shur-Fen Gau et al, 2012). Given the relationships between stress and low marital satisfaction to marital dissolution, it would not be surprising if parents of children with autism, experienced high rates of divorce (Gottman, 1994). The media has long cited an 80% divorce rate for parents of children with autism, but there is little empirical data and no epidemiological investigation to confirm or further explore the relationship between rearing a child with autism and divorce. According to Freedman and Naseef's study, divorce rates of parents with children with autism do not, in fact, differ from that of other parents (2012). However, the tension rising from the stress of caring for a child

with autism, opposing views on disability, and the best course of treatment may be disruptive to the parents' marriage (Gray, 2003; Moreno, 1995).

### **Parental Self-Efficacy and Competency**

A review of the literature on parental self-efficacy has shown it to be a critical element in parenting and one that is closely associated with parental competence. Parents who demonstrate high levels of parental self-efficacy tend to demonstrate high levels of parental competence (Jersualem & Mittag, 1995; Teti & Gelfand, 1991). The two values combined are associated with positive developmental outcomes in children and parental self-esteem. However, parents of children with autism tend to experience lower parental competence than parents of both typically developing children and children with other disabilities (Rodrigue et al., 1990).

The degree to which parents presume to fulfill their roles as caregivers and meet parental obligations constitutes parental self-efficacy (Hastings & Brown, 2002; Johnston & Mash, 1989; Jones & Prinz, 2005; Teti & Gelfand, 1991; Weaver, Shaw, Dishion, Wilson, 2008). Accomplishments, vicarious experiences, verbal persuasion, and physiological states construct the parental experience (Bandura, 1977). Guided by social learning theory, parental self-efficacy has its roots in Bandura's self-efficacy theory which refers to how an individual's belief in their ability to successfully complete tasks influences their performance. In

other words, self-efficacy predicts behavioral change. Bandura viewed self-efficacy not as a fixed trait but one that was subject to change based on demands and personal development (1977). Success and failure experiences have an impact on levels of perceived efficacy resulting in lowered parental self-efficacy in parents who experience heightened stress.

Parental self-efficacy has been strongly linked to parental competence throughout the literature. While the two terms are often used interchangeably a review of the literature on parental self-efficacy determined that parental self-efficacy and competence are two distinct concepts with competence often described as a pre-cursor to parental self-efficacy (de Montigny & Lacharite, 2005; Gilmore & Cuskelly, 2008; Johnston & Mash, 1989). While some authors argued that the primary distinction between parental self-efficacy and parental competence lies in whether the evaluation comes from internal (parent) or external (society) sources, most authors viewed parental competence as a collection of skills and strategies independent of who is making the judgment (de Montigny & Lacharite, 2005; Jones & Prinz, 2005; Sabatelli & Waldron, 1995).

Perception of parental self-efficacy predicts competency in the face of environmental demands, informs the way in which individuals interpret and handle challenges, and predict future behavior. Higher parental self-efficacy is associated with higher parental competence and the two factors together are

associated with a variety of positive factors for both parent and child (Jerusalem & Mittag, 1995). Parents who feel confident in their parenting abilities are more likely to engage in effective parenting practices that help promote positive developmental outcomes (Gilmore & Cuskelly, 2008; Jones & Prinz, 2005). They are also more likely to have children with higher levels of positive adjustment and a lowered incidence of behavior problems (Jerusalem & Mittag, 1995; Weaver et al., 2008). Conversely low levels of parental self-efficacy are associated to higher levels of parental self-doubt, higher anxiety in adversity, and a higher likelihood to interpret challenges as threats. Additionally, depression and the challenges of raising children with health problems may threaten self-efficacy and the parent's emotional availability to engage in positive parenting practices. These factors also heavily influence the parent-child relationship with higher levels of parental self-efficacy being associated to increased quality of child interactions, parental warmth, and responsiveness (Jerusalem & Mittag, 1995). Affective priming theory maintains that cognitive schemas are built on our memories of past experiences which are stored with the affective state that accompanied them (Bower, 1981).

Bandura's self-efficacy theory builds on this foundation and argues that depression predisposes people to lowered self-efficacy and negatively affects performances based on the selective activation of memories of failure experiences (1989). Children's behavior and parents' inability to manage behavior problems

significantly increased levels of stress and decreased levels of psychosocial health (Magaña & Ghosh, 2010). Meanwhile, others' view that parents were unable to manage their child's behavior compounded the stress for many (Randall & Parker, 1999). Thus, parents struggle lies not only in managing maladaptive behavior but in what this says about their parental competence.

A number of studies have indicated parental stress and depression are negatively correlated with parenting cognitions such as self-efficacy (Hassall, Rose, & McDonald, 2005; Kuhn & Carter, 2006). Parents with high parental self-efficacy are more available to guide their children's development without experiencing significant emotional strain while those who with low parental self-efficacy might struggle to meet their child's demands and subsequently experience increased depression and family stress. In fact, not only is lower self-efficacy predictive of parenting stress, it is more prevalent in mothers with a history of depression (Maciejewski, Prigerson, & Mazure, 2000). On the other hand, higher parental self-efficacy serves as a protective factor that mediates risk factors such as symptoms of depression and child behavior problems (Gilmore & Cuskelly, 2008; Teti & Gelfand, 1991). Interestingly, depression had no effect on parental competence independent of parental self-efficacy meaning parents may acquire skills and improve competency levels even if they do not feel efficacious (Teti & Gelfand, 1991).

Several measures exist to assess stress, parental self-efficacy, and competence. Most prevalent among these are the Parenting Stress Index (PSI) and the Parental Sense of Competence Scale (PSOC). The PSI measures stress in child and parent domains while the PSOC assesses parental estimations of their parenting abilities and their satisfaction with that role (Johnston & Mash, 1989). Although the PSI has adequate construct validity and high internal consistency, there is limited data on its psychometric properties, and at the time the current study was conducted no normative data existed. The PSOC, on the other hand, is not only one of the most widely used measures of parental self-efficacy, it has strong internal consistency, reliability, test-retest reliability, and more recent studies have established a normative sample (Jones & Prinz, 2005; Gilmore & Cuskelly, 2008).

The research has emphasized the relationship between parental self-efficacy, parental depression, and child behavior problems with studies showing how these factors can serve as mediating factors for each other. For example, using the PSOC, Hastings and Brown found parental self-efficacy mediated the effect of child behavior problems on maternal anxiety and depression and moderated the effect of child behavior problems on symptoms of mood disorders (2002). Rezendes and Scarpa found similar effects where parenting stress mediated the effect between child behavior problems and low parental self-efficacy while low parental self-efficacy mediated the relationship between

parenting stress and increased depression and anxiety. Specifically, children's behavior problems were related to higher parental stress which accounted for lowered parental self-efficacy (2011). Studies such as these and research on parental competency have helped inform interventions designed to improve parental well-being. Integrating this research with empirically supported parenting strategies within normal family routines have resulted in reductions in parenting stress and increases in parental self-efficacy (Keen, Couzens, Muspratt, & Rodger, 2010).

Parents of children with autism report lower levels of parental competence than parents of both typically developing children and children with other disabilities (Rodrigue et al., 1990). Clinicians have responded to this finding with parenting classes in an effort to increase knowledge and therefore self-efficacy. Several programs have demonstrated that participation in parenting classes helps decrease parental stress, increase parental self-efficacy, and improve parent-child relationships (Farber & Maharaj, 2005; Levac et al., 2008). A phenomenological study of Child-Parent Relationship Training as experienced by Latino parents found that parents who participated in 10 week training on child-focused play experienced a reduction in feelings of frustration, increased sense of parenting self-efficacy, and a reduction in maladaptive child behaviors, increase in pro-social behaviors (Garza, Kinsworthy, & Watts, 2009). Other parenting curriculums such as the Chicago Parent Program, have benefitted from the

research on parental perceptions of their abilities. This intervention was found to be successful in increasing parenting self-efficacy in parents who attended at least half of the 12 offered sessions as well as reducing child behavior problems, maintaining gains at follow up a year after the intervention (Gross et al., 2009).

The literature offered interesting insights into the relationship between self-efficacy and performance that researchers should keep in mind when gathering data. Various studies demonstrated changes that, though positive, did not reach significant levels. Upon closer examination, researchers found that in general parental efficacy levels will only increase when they were low at baseline. In other words, interventions, even those focused specifically on parenting factors, do not seem to have a significant effect on parents who are already doing well (Keen et al., 2010).

The research on parental self-efficacy clearly supports Bandura's original research and theories on self-efficacy which indicated that one's expectations and past experiences shape emotion response, cognitions, and behavior (1977). Coping responses, from energy expended to the coping mechanism chosen, depend on these expectations. Stress and low self-esteem in parents are linked to less than optimal parenting, impeded child development, and higher rates of child psychopathology and antisocial behavior (Llewellyn et al., 2005; O'Connor, 2002). Furthermore, it interferes with adherence to intervention and counteracts



the efficacy of early interventions (Osborne et al., 2008). Knowledge of how self-efficacy beliefs function and develop can contribute to a greater understanding of parental behavior and also help focus interventions to diminish anxiety and structure successful interactions. Living with a child with behavioral, developmental, and social challenges may diminish parental perceptions of competency, effective parenting techniques, and contributes to the continuation or exacerbation of problems with family functioning, behavioral regulation, and developmental outcomes (Lovejoy, Verda, & Hays, 1997).

### **Family Functioning**

Some parenting stress is considered adaptive. However, elevated stress levels that negatively affect parental well-being and family functioning (Higgins et al., 2005; Kuhlthau et al., 2010; Shur-Fen Gau et al, 2012). Parenting stress and children's symptom severity is predictive of parental depression and poorer levels of well-being and family functioning (Phetrasuwan & Shandor Miles, 2009).

Family functioning as measured by the FLIS goes beyond stress to evaluate the extent to which a child's symptoms disrupt routine family activities. Even for parents of children who are considered high functioning, the child's limited social skills, rigidity, and difficulties with pragmatic language frequently interferes to family functioning.

There are several clinical instruments that measure the effects of living with children with autism on family functioning. A review of the literature found the most commonly used instruments to measure parent stress were the Parenting Stress Index (PSI) and the Questionnaire on Resources and Stress (Boyd, 2002). During the current review, the most commonly found measurements of stress were the Parenting Stress Index and the Family Adaptability and Cohesion Evaluation Scales -III (FACES-III).

The Parenting Stress Index (PSI) is a 36-item self-report measure that assesses parental stress using scales to measure parental distress, parent-child dysfunctional interactions, difficult child characteristics and parental competence that altogether measure parental stress (Abidin, 1977). It has adequate construct validity and high internal consistency, with an alpha of .80-.91 and a test-retest reliability of .68-.85. However, there is limited data on its psychometric properties and some debate about whether there are two or three factors. Furthermore, the PSI does not allow for measurement of positive or protective factors. All reviewed studies where the PSI was used to evaluate stress levels in parents of children with autism revealed high levels of parental stress.

The Family Adaptability and Cohesion Evaluation Scales -III (FACES-III) is 40-item self-report scale, it includes scales to measure current and ideal functioning, family cohesion, and adaptability. The FACES-III has a test-retest

reliability of .80-.83 and an overall alpha of .68. Like the FLIS, used in this study, it includes questions on spirituality, and social support (Olson, 1991). With the exception of one study which found increased cohesion in families of children with autism, all reviewed studies found lowered family cohesion and adaptability for families living with children with autism (Rodrigue et al., 1990). Despite the high levels of cohesion, families nonetheless reported difficulties carrying out family activities and heightened stress.

Although the PSI and FACES-III both appear to be reliable measures, the FLIS was chosen based on its significantly shorter format with fewer items and a Likert scale with a smaller range. Additionally, the FLIS had an alpha that was comparable with the PSI and higher than the FACES (Mian, Soto, Martinez-Pedraza, Maye, & Carter, 2012). Though test-retest reliability was lower than the PSI this measure nonetheless has acceptable levels. Moreover, the FLIS allows for measurement of positive factors including spirituality, marital cohesion, and personal growth in addition to the measurement of impairment, the combination of which is important when assessing families and making treatment recommendations.

The Family Life Impairment Scale is a parent-report measure that assesses the degree to which a child's behavior, personality, or special needs limit participation in typical family activities or negatively affect the parent and family

(Briggs-Gowan & Carter, 2010). In addition to the published scale and the validation of the FLIS for use in families with toddlers with autism, a review of the literature found only seven published articles and one dissertation in which researchers used the FLIS to assess family functioning. Two studies used the FLIS as a tool to validate the presence of behavior problems (Wakschlag et al., 2006; Wakschlag & Hans, 2012), and another to demonstrate how family stress is predictive of higher likelihood to seek assistance from health providers (Ellingson, Briggs-Gowan, Carter, & Horwitz, 2004). The remaining four studies and dissertation examined the effects of family functioning, stress, and child behavior more directly.

The authors of the FLIS conducted research on parental stress associated with raising children with a variety of both internalizing and external behaviors prior to developing the FLIS. Though they had previously relied on the PSI to assess parental stress then developed the FLIS when studying the persistence of parent-reported social-emotional and behavioral problems in infants and toddlers. As a brief measure, in that original study it was designed to evaluate the effects of maladaptive behavior on a normative sample of children (Briggs-Gowan et al., 2006). Results demonstrated that behavioral problems are not transient and that family life impairment was a significant predictor of persistent social and emotional problems in parents. A review of the use of the FLIS in the literature found similar results with increased incidence of behavior problems being

associated with higher levels of family impairment reported by parents (Carter, Ben-Sasson, & Briggs-Gowan, 2011). Other factors that were associated with family impairment included sensory over-responsivity because of the limitations it places on family activities, as well as internalizing and externalizing symptoms (Ben-Sasson et al., 2013; Carter et al., 2010; Carter et al., 2011). Externalizing disorders were linked to impairments in social skills (Carter et al., 2010). On the other hand, increases in social skills as measured by the Vineland and developmental skills as measured by the Psychoeducational Profile-III (PEP-3) were associated with lower levels of family life impairment (Lambert 2012). Ben-Sasson and colleagues found that stress and family functioning did not change over time, but the results showed considerable variability between respondents and the author acknowledged that baseline effects could account for low rates of change (2013). Families that started with high levels of stress and impairment continued to experience high levels of impairment while families with low levels of stress continued to experience lower levels

The literature on positive experiences related to raising a child with autism is limited but growing. Although research has found that parents report greater levels of stress than enrichment, a growing number of measures are including scales to measure positive effects of caring for a child with a disability (Phelps et al., 2009)(Hastings et al., 2005). The Family Life Impairment Scale (FLIS) used in this study includes two scales to measure potential positive growth one focused

on the relationship between caregivers and the other on spirituality. These seem to be the two areas of growth most commonly cited in the literature (Gray, 2002; Hastings & Taunt, 2002; Skinner, Bailey, Correa, Rodriguez., 1999).

### **Cultural Considerations**

Ecoculture theory provides a framework used to examine the sociocultural environment and its effects on treatment and family dynamics. Previous research using this approach suggested that interventions be adapted to suit the attitudes, goals, and systems that comprise the ecocultural niche of a family (Gallimore, Coots, Weisner, Garner & Guthrie, 1996). The interaction between stressors, the family's risk factors and vulnerability, patterns of functioning, resources, evaluation of the stressor and coping mechanisms determine how families adjust to stress.

Latinos are the fastest growing segment of the U.S. population (U.S. Census Bureau, 2012). However, health disparities research confirms Latino immigrant families underutilize evidence-based parenting interventions, particularly without mandated participation (Flores, Olson, & Tomany-Korman, 2005). The growing influx of immigrant families heightens the need for clinicians to recognize how immigrant groups manage mental health disorders and disabilities and how membership in these different groups informs the clinician and the patient's interpretation of what it means to have a disability. This

knowledge is especially salient given the strong role culture plays in how parents approach and handle adversity, whom they turn to for help, and in guiding the particular parenting practices (Shriver & Allen, 2008). The current research focused on Latino families, as growing rates have necessitated a better understanding of how this group is affected by and how they process autism spectrum disorders. Three of the dominant Latino values, religion, *marianismo*, and *familismo*, are especially salient to the nature of this study given their effects on family functioning and role in coping.

Religious beliefs are not only connected to one's faith system but also affect how one views gender roles, family obligations, and the concept of sacrifice—all relevant to the subject of this study. Religious coping has also been found to have a mediating effect and help reduce stress and depression in parents of children with autism (Hastings et al., 2005; Iland, 2007; Moreno, 1995). Some cultural groups, including Latinos, Native Americans, African Americans, and Asians, support the belief that disabilities are a direct result of the family's actions, either as a punishment or blessing (Moreno, 1995; Skinner et al., 1999; Rogers-Dulan & Blacher, 1995). For Latino parents, religion may be a way to find meaning in a child's diagnosis and aid with coping.

One construct that guides maternal attitudes within Latino families is that of *marianismo* in which the mother's goal is to emulate the Virgin Mary,

sacrificing and suffering for their child (Comas-Diaz, 1987). Parenting a child with a disability provides the opportunity to prove herself as an extraordinary mother who sacrifices her own needs in order to take care of her child, considered a blessing from God (Magaña & Smith, 2006; Skinner et al., 1999). For Latino mothers of children with disabilities, committing to the role of *marianismo* may include acting as social brokers for children who cannot communicate their own needs. However, adhering too strongly to *marianismo* may contribute to, and maintain, higher levels of maternal stress.

*Familismo* embodies the collectivist nature of Latin American countries, emphasizing the importance of close relationships, family cohesion, and cooperation (Marin & Triandis, 1985). Degrees of *familismo* not only help families cope with stressful situations but also predict the utilization of treatment services for Latinos (Blacher, Lopez, Shapiro & Fusco, 1997). Traditionally, high levels of cohesion, when parents are over-involved and overprotective, have been associated with negative effects on the growth and independence of children (Minuchin, 1974; Seligman & Darling, 1997). However, parents of children with autism who rate their families as enmeshed are more likely to implement social support as a coping mechanism during times as crisis. Therefore, an “enmeshed” family style may be more adaptive for families who face extreme challenges such as families with children with disabilities (Altiere & Kluge, 2009). For these



families, close family relationships and interactions that revolve around the importance of family unity become a coping mechanism.

The research has come a long way from the time when parents, mothers specifically, were believed to have caused autism in their children. First described by Kanner in 1949, the “refrigerator mother” theory was further developed by Bettleheim (1967), who contended that autism was an emotional disorder caused by unresponsive mothers. Though this theory has been widely discredited, some Latin American countries with a more psychogenic approach to autism continue to treat autism from a psychoanalytic perspective (Cecchi, 2005). This line of thinking may contribute to delays in seeking treatment. Parents may be reluctant to have their child identified as having autism because of the potential personal repercussions including being blamed for the disorder. Mothers who attribute their child’s disorder to their own perceived shortcomings or who experience mental or emotional distress as a result of their child’s disability may be less likely to seek help (Magaña & Smith, 2006).

The cultural values discussed herein are by no means comprehensive nor do they apply to the same extent to all Latinos but provide a framework to recognize how culture informs the worldview of the participants. Differences between and within groups exist but understanding these constructs is important given the tendency for parents to adhere more closely to cultural traditions in the

face of a traumatic event (Moreno, 1995). Overall, the relationship between culture and disability significantly affect how diagnosis and treatment are understood, how help is procured, and how parents cope with having a child with autism, as well as how these factors cumulatively affect family functioning.

In addition to delays in diagnosis, minority groups face a number of social, cultural and economic barriers that may limit access to services. Limited understanding of and involvement with the school system, poor residential stability, insufficient support for students, few incentives to continue with education, and barriers to higher education occurring as a result of immigration status were all found to negatively affect Latinos' educational experience (Bohon, Macpherson, & Atilas, 2005). Many of the day-to-day interventions children with autism receive occur not in out-patient settings but through the school system as part of their individual education plans.

Outside of school services, which are generally protected regardless of legal status, undocumented legal status creates a particularly troubling set of complications. Accessing services necessitates multiple interactions with systems at various levels –an experience that at its best is uncomfortable and at its worst is an insurmountable barrier for families who lack legal status. Regardless, both legal and illegal migration status have been documented to be a source of significant stress for Latino families. Navigating an unfamiliar system while

simultaneously dealing with the psychological, social, and economic cost of migration can take a significant toll on families. Furthermore, immigrants with undocumented legal status face numerous barriers and are often reluctant to obtain services from government agencies fearing it may jeopardize their living situation. These factors not only act a barrier but generate greater stress for the family resulting in additional risks for the child (Sanchez, 2006; Welterlin & LaRue, 2007).

The U.S. Census Bureau (2012) describes the situation where no one in the home over the age of fourteen speaks English well enough to navigate mainstream institutions as linguistic isolation. Linguistic isolation contributes to a vulnerability experienced not only by the parents but the children who depend on them for resources. Language affects parent's communication with pediatricians even with translators present resulting in a mistranslation or omission of up to 23%-44% of questions (Flores, Abreu, Schwartz & Hill 2000). Sometimes, children's delays in language are mistakenly attributed to English language learner status delaying the diagnostic process. Though autism screening and diagnostic tools are available, they are limited in number and even then, are often not normed on Spanish speakers. Parents who cannot fluently speak and understand English may struggle to explain their child's symptoms and the language barrier contribute to the delay in diagnosis, interfere with the delivery of interventions, and decrease generalizability of skills from school to home. Thus,

language barriers act a deterrent for parents to initiate or fully participate in communication with the child's school and therapists (Bohon et al., 2005).

Despite the above described variables, it is important to note that the majority of Latinos in the U.S. are in the country legally, have completed high school, are employed, and live above the poverty line (Markus & Kitayama, 1991). However, the sample used in this study identifies more with the barriers described herein and as first generation immigrants tend to have lower levels of education and lower to middle socioeconomic status.

## **Treatment**

There is a substantial amount of literature on the comprehensive and evidence-based treatments associated with lasting improvements in individuals with autism. Until recently, however, there has been no known cure for autism. In fact, some clinicians argue the term "cure" is not appropriate given the neurobiological basis of autism. However, a recent study found evidence to support that some children may outgrow the diagnosis (Fein et al. 2013). Regardless when provided with the proper treatment, which may include biomedical, nonmedical, educational, and evidence-based interventions, all children are capable of some progress.

Most evidence-based treatments commonly used with children with autism are based on behavioral principles (Brentani et al., 2013). For example, Applied

Behavioral Analysis (ABA) is derived from the principles of operant learning and is used to develop adaptive skills and aid in the acquisition of new skills through the use of repeated trials, reinforcement, and functional assessments. TEACCH, a classroom based program, uses structured teaching to organize the environment, maximize visual strengths, and teach skills. For older or higher functioning children, cognitive behavior therapy has been effective for modifying behavior and reducing anxiety and depression –frequently experienced by children who are more cognizant of their limitations and peer rejection (Brentani et al., 2013). Regardless of the chosen intervention, practitioners and researchers agree that early diagnosis and early interventions are key to helping children to develop adaptive behaviors and gain skills in the areas of core deficits (National Research Council, 2001)

### **Family Interventions**

The rationale for including the family in treatment is two-fold, not only does it increase the generalization of acquired skills into the natural environment, but it also helps address the parent's needs and concerns about the parenting experience. Research on families with children with autism spectrum disorders previously focused on the parent's effect on the child, not the child's effect on the parent. However, just as family functioning styles affect the child, the child's

own development in turn affects family functioning resulting in a bidirectional influence (Altiere & Kluge, 2009).

Several studies have demonstrated positive effects for the entire family associated with their inclusion in treatment. For instance, family intervention programs which use psycho-education, skills training, and parenting techniques, have been found to reduce parental stress and symptoms of depression and increase parental satisfaction, competence, and improve various family factors including those related to family functioning, involvement, and coping (Horst, Werner, & Werner, 2000; Katsikitis, Bignell, Rooskov, Elms, Davidson, 2013; Keen et al., 2010). Programs that focused specifically on enhancing the quality of parent-child relationship by having parents practice new skills with their child demonstrated the largest effects on both child and parent behavior and skills (Kaminski, Valle, Filene, & Boyle, 2008). The positive effects may be explained by the results found in Bandura's initial research on efficacy in which he noted that individuals who merely observed but did not engage in the learned behavior had fewer gains in performance and self-efficacy expectations than those who engaged in the behavior (1977).

### **Recreation**

Families with children with autism are less likely to engage in recreational activities and participate in activities as a whole family (Bristol et al., 1993; Smith

et al., 2010). Parents cited loss of family socializing experiences as one of worst effects of autism on families and parents expressed significant concerns about the effects of infrequent family activities on the whole family (Gray, 2002). Despite the often cited benefits of engaging in family recreation, including its contributions to family cohesion, marital stability, satisfaction with family life, and benefits for child development, simply recommending families engage in more activities together is not enough (Mactavish & Schlein, 2000; Mannell & Kleiber, 1997). There are barriers to successful participation in family recreation including the aforementioned parental stress, child behavior problems, as well as limited time due to time spent on child-care activities. An analysis of how mothers spend their time found that while mothers of children with autism spend similar amounts engaged in activities in and out of the home, but sacrificed personal leisure and recreational pursuits to meet the additional demands of their child's care (Smith et al., 2010). Thus, in order to address the recreational needs of children and their families, factors for facilitating its introduction must be considered. Children may require programs that provide a stronger focus on skill development and that offer support for parents to help them develop strategies to involve the whole family in a range of activities.

Children with autism struggle with social engagement and particularly with age-appropriate play (American Psychiatric Association, 2013; Hobson & Lee, 1998). Recreation, play at its core, is a natural part of human behavior is an

important part of children's cognitive and social development (Griffiths, 2005; Piaget, 1951; Vygotsky, 1978). Play provides the context in which children can experiment with social experiences, emotional responses, and consequences that can then bring resolution in real-life situations. Thus, play serves as the first step toward abstract thinking, a concept that is difficult for most children with autism (Vygotsky, 1978.)

Games have shown to have positive therapeutic outcomes for children and adolescents and have long been used as a therapeutic tool (Griffiths, 2003). Games, particularly those that are interactive, are powerful tools for social interaction and learning. They help children set goals, practice skills, and use feedback to encourage behavioral change (Griffiths, 2002; Lieberman, 2006; Pearson & Bailey, 2007).

One of the most prevalent types of games played by children and adults alike are video games. Compared to their predecessors, contemporary video games have a pervasive social nature and interactive design, both of which help appeal to consumers, develop children's play skills, and allow parents to be a part of the process (Granic, Lobel, & Engels, 2014). An additional benefit of an intervention centered on video games, is less likely to be associated with less stigma compared to traditional therapy. Conversely, it may alienate some parents who might see it as more of a play-time and not recognize the potential benefits.



In order to avoid this, intervention and education are needed at the parent level before incorporating video games into treatment. The current intervention is by no means intended to replace traditional therapeutic approaches for children with autism, rather, it is proposed as an augmentative therapy to address the stress experienced by parents, the barriers to positive family functioning, and increase opportunities for family interaction.

Often, people who are resistant to traditional didactic approaches to learning are more open to engaging in play and interactive games (Lieberman, 2006). The interactive component found in games heightens the level of involvement leading to higher rates of retention compared to more traditional approaches to teaching and learning (Lieberman, 2006). The goals targeted in the current intervention, as in others that use video games as part of treatment, are not related directly to gaming abilities but, as in recreation, target the incidental learning that occurs when playing together as a family.

Much of the literature on the effects of video game play has focused on negative consequences such as video game addiction, aggression, and isolation (Griffiths, 1999; Rosas et al., 2003). These concerns are not without merit, especially given the emerging research on children with autism's propensity toward video game addiction (Mazurek & Engelhardt, 2013). However, more recently and with the advent of interactive games, an emerging field of study has

focused on the promising use of video games to promote healthy interactions, skill acquisition, and shape behavior. Gentile and colleagues (2009) summarized findings from correlational, longitudinal, and experimental studies and found that playing pro-social video games consistently related to and predicted pro-social behaviors in the immediate future, as well as long term. Even violent video games, when played cooperatively as opposed to competitively, help develop subsequent pro-social, cooperative behavior outside of the game context (Ewoldsen et al., 2012).

There are several reasons both children and parents are drawn to video games, many of which are beyond the scope of the current research. One of the benefits of gaming that is relevant to the research questions is the effect of self-esteem and self-efficacy. Research has shown that playing video games can contribute to raising self-esteem through the success brought on by practice, overcoming obstacles within the game, and perceived control (Griffiths, 1997). Interactive games help make the experience more immersive allowing players to explore, make choices, and experience the consequences and rewards. The feedback provided by the gaming system allows players to build skills and positive experiences. To maximize the potential for utility in clinical settings, the positive associations need to be generalized beyond the game and include the social interaction and self-control, both of which make the game more enjoyable and the play more successful. Players develop positive attitudes about the learning

that occurs during interactive games and sustain these attitudes about what they learned. Positive emotional attributions are especially likely to occur when the rewards of the game focus on the effort, social interaction, and intrinsic rewards related to enjoyment as opposed to extrinsic rewards (Lieberman, 2006). For parents in the current investigation there were no extrinsic rewards for playing and managing behaviors only the intrinsic rewards of experiencing greater efficacy in managing behaviors and enjoying a recreational opportunity with their family.

Teaching and practicing pro-social skills in the recreational setting enhances relationships with both peers and family. Coyne, Padilla-Walker, and Stockdale's (2011) study on the associations between co-playing video games and family outcomes was the first study of its kind to demonstrate the positive effects of playing video games with parents. The researchers found positive associations between co-playing video games and parent-child connectedness, particularly for girls. Girls who played video games with their parents also demonstrated lower internalizing and aggressive behavior and an increase in pro-social behavior. However, the sample was comprised of a majority of Caucasian parents of teenage children making it difficult to generalize the findings to the current sample. Furthermore, these findings were not replicated for boys, who are diagnosed with autism with more frequency. Despite these limitations, this study

is a useful example of the positive effects parent-child recreational opportunities may have on child behavior and family functioning.

### **Video Game Interventions**

There is limited research on the use of video games with children with autism. Most of the existing research has focused on the effects on motor development and not on the development of pro-social behavior, adaptive behavior, or family interaction as is the case with the current study. However, the benefits of motor planning and proxemics should not be dismissed. An examination of the effects of using a video game that uses an input device to register movement with a social partner found an increase in empathic gestures and number of utterances. Interestingly, though participants were all female undergraduates, the researchers used the Autism Diagnostic Observation Schedule, to code socio-communicative behaviors (Lindley, Le Couteur, Bianchi-Berthouze, 2008).

Demarest (2000) gave an example of how video games have been used with children with autism to help with the development of different skills including language, academics, self-esteem, and social skills, visuospatial skills, and coping skills. Language skills improved through the discussion of games and gaming technique and led to increased sharing, following and giving directions, and answering questions about the games. Having a common ground on which to build conversation also aided in the development of social skills given the

popularity of video games with other children. Although Demarest's account provided some useful starting points, as an anecdotal account, it did not use scientific research methods but was based on parental observations. Despite its limitations, it is notable for its mention in several of the peer reviewed journals and is a starting point on which to build interventions.

Other researchers have found similar positive effects related to social development and behavioral outcomes. Ferguson and colleagues' 2013 evaluation of a group intervention which indicated that using video games in conjunction with behavior skills training can be effective in teaching sportsmanship skills in children with autism. Specific to the parent-child relationship, another study examined the interaction between typically developing children and their parents while engaging in play with a board game and Nintendo's Wii (Chiong, 2009). The researchers observed themes that they categorized into pro-social and asocial behavior. Pro-social behavior included children explaining the games to the parents, parents asking questions to test the child's grasp of knowledge, complimenting each other's actions, and parents having the child discuss the steps aloud. Asocial behavior included difficulty understanding how to play the game, child protests against parent control, parental failure to respond to children's questions or requests for help, and the child taking the controller from the parent. Although Chiong focused her work on neurotypical children, her work shares multiple similarities with the current study providing a point for comparison.

There is a paucity of information on the use of video games with children with autism. Emerging research points to many potential benefits for social development and motor planning with some caveats about the risks of aggression, addiction, and increased sedentary time. It is not clear why video games are so appealing for children with autism, but perhaps their relative strengths in visual perception may make visual media inherently more rewarding (Lieberman, 2006). Combined with the limited social demands and possibility for entertainment, it is perhaps no surprise that children with autism tend to spend more time than their typically developing peers using screen-based media (Mazurek & Engelhardt, 2013). At an average of four-and-a-half hours daily, this greatly exceeds the recommended screen time by the Committee on Public Education (2001). Increased time spent on media use results in significantly less time engaged in social or physical activities and can lead to other negative consequences. In particular, some researchers have pointed out to the higher risk factors for children with autism to develop symptoms of video game addiction (Mazurek & Engelhardt, 2013).

Though not classified as an actual disorder, video game addiction is characterized by some of the same behavioral features associated with addiction including the salience, tolerance, withdrawal, relapse, changes in mood, and conflict (Gentile et al., 2009; Griffiths, 2005). Aside from behavioral signs of addiction, Mazurek and Engelhardt cited an increased risk for problematic

behaviors. However, beyond difficulty disengaging from games, they did not elaborate on what how problematic behaviors manifest themselves. Disengaging from games may be especially challenging for those for whom video games have developed into a restricted interest or preoccupation.

Although much of the research on video games has focused on the negative effects of increased sedentary time, aggression and social isolation, these factors may be controlled by managing the choice of games. Parents can counteract these effects by choosing games that requires exercise and are played with others to promote social interactions. Such was the case with all of the games used for the current intervention. However, outside of the clinical setting, not only are parents seldom engaging in gaming, they are often unaware of the kinds of video games played by children. In a 2004 study by Gentile, Lynch, Londer and Walsh, 43% of adolescents reported that their parents did not control their usage of video games at all. It is possible that parents experiencing high levels of stress, low self-esteem, and low parental competence may find it more difficult to confidently regulate their child's media use (Bickham et al., 2003).

One significant limitation in the literature was that the vast majority of articles that examined effects of playing video games focused on the experience of adolescents, making it difficult to generalize to younger children, such as those who participated alongside their parents in this study. (Coyne et al., 2011). Additionally, while much of the research described the potential benefits for

children and adolescents few authors explored the potential benefits for parents even when including them as participants in interventions.

Few traditional games can boast the cross-generational appeal and long duration of interest that video games offer. The preceding review argues that, in the right context, video games can have a positive and therapeutic effect for a broad range of groups including families of children with autism. Aside from the effects on motor planning and visuospatial functioning, which until recently has been the focus of research with this population, emerging literature has elucidated the potential benefits for social development, self-efficacy, and the parent-child relationship. Thus, through the proposed intervention, parents and children alike are able to take advantage of a recreational opportunity while simultaneously developing skills and their relationship in this recreation-education paradigm.



## **Chapter III**

### **Methodology**

Interactive games can help motivate individuals to learn, including those who initially were not particularly interested in the subject matter (Lepper & Henderlong, 2000). The developers of the pilot intervention program evaluated in this study believed that children's interest in video games would be a motivating factor. They designed the program to find a method to encourage these children to follow rules and directions and continue participating while at the same time letting parents practice behavioral techniques in an environment where children were motivated. In their selection of video games, care was taken to exclude video games that promoted aggression and included only those that promoted exercise as an integral component of player participation. Data gathered from this pilot program was used for the present study to evaluate the effectiveness of this intervention.

#### **The Pilot Intervention Program**

Consent for participation in the original study was obtained in a secure private office to ensure confidentiality. Consent form included a brief explanation of the purpose of the study, the procedures, over view of the brief-self report scale, level of risk and benefit involved in participation, exactly how information

gathered would be kept confidential, and that they could chose not to participate in the study or withdraw at any time without any penalty. Participation by all parents was voluntary and without remuneration or incentive to participate. A copy of the signed consent form was given to the parent for their records. During this appointment parents were given an opportunity to ask questions and be assured of their rights to privacy and confidentiality. Consent and Measures were administered individually to each parent in their language of preference (Spanish or English) by bilingual and bicultural researchers. All the instruments not already available in Spanish were translated using the translation/back translation method. Following consent to participate pre-tests including the Vineland-II, PSOC, and FLIS were administered. Post-testing took place after 8 intervention sessions and whenever possible was conducted by a clinician other than the one that delivered the intervention to avoid tester bias. Results were then entered into a database, de-identified, and analyzed using the Statistical Package for the Social Sciences 22.00 (SPSS). Data was stored in a password-protected computer at the site of intervention. Information was de-identified and stored using a serial number.

Each intervention round was 10 sessions which included 8 intervention sessions lasting an hour each and 2 sessions for pre and post testing. Nintendo's Wii was chosen as the gaming console for this intervention given the range of games available, the wireless controller which can detect motion and rotation in three dimensions, and the accessibility to the general population (Pearson &

Bailey, 2007). The games selected included Wii Sports, Wii Fit, Just Dance, and Just Dance Kids. These games were chosen because of their emphasis on movement, the adjustability of difficulty, and the possibility of enjoyment for any age. Wii sports contains five sports games which are all accessed from a well-designed menu which has a clear layout and large icons.

Prior to the beginning of the program avatars were created using the video game console for each family member based on physical appearance and favorite colors –information which was obtained during pre-testing. Social cognitive theory has demonstrated the way in which attractive role model characters that are similar to the player can teach by example (Bandura, 1997, 2004). The researchers hoped that having an avatar, called a Mii, with whom the children could identify would help the children understand that they were not only playing the game on the television but that this could be generalized into their family life at home.

The room was set up the same way prior to each gaming intervention. A television was placed in the front of the room and connected to Nintendo's Wii gaming system. Various games, and a Wii Fit board were available for selection. Selecting appropriate games was acknowledged to be a key part of promoting healthy interactions. Funk, Germann, and Buchman (1997) provide basic guidelines for consideration when choosing games. Among these are to need to

consider the educational or therapeutic objective, the type of game, the level and nature of involvement, the rules, the role of luck, the level of difficulty, competition, duration, number of players, facilitators role, setting, and characteristics of the participants. All of the games chosen for the current intervention required a degree of exercise, a minimum of two players at any given moment, games that had a clear beginning and end. Most games had a duration of less than 5 minutes for each turn.

Rules and reinforcement boards, a timer, and a set of 1lb, 3lb, and 5lb free weights were available and their use encouraged where appropriate. Sessions were each 60 minutes in length. Each session began with greetings and an overview of the rules and then concluded with a wrap-up during which time each player reported their favorite part of the game. Responses ranged from a discussion of the game itself, personal successes and the interaction with the family.

Rules during session were as follows 1) Share 2) Wait your turn 3) Good voice volume 4) Personal Space and 5) Have fun. All of the rules were stated within a positive format to inform children of the expected behavior. After the program began, it became clear that children needed reminders about what behaviors were prohibited and thus rules including “no hitting” and “no rude words” were added. However, these were presented in a visual format that de-

emphasized them to keep the interaction positive and not too restrictive or punitive. Children were intermittently reinforced for following the rules with a behavior star chart. The reward for filling up the board with a pre-determined amount of stars was the privilege of choosing the next game or the game during the last 5 minutes of free-play. The review of rules and behavior reinforcement were initiated by the therapist and gradually taken over by the parents who played with the children. The intervention was facilitated by two therapists at a time, both doctoral students with experience working with children with autism. Therapists served as models for behavior management. However, the focus was on the interaction and the behaviors as they were occurring rather than a discussion of the behaviors at home or through the use of a functional assessment. In other words, instead of parents providing historical examples of behavior, they learned through in vivo experiences.

Adult responsivity, alternative communication methods, environmental arrangement, offering choices, imitation, and turn taking are all strategies that parents may use in their every-day interactions with their children to encourage social and communication development and were therefore encouraged throughout the program (Keen et al., 2010). Given that children with autism benefit from predictability and structure a visual schedule and visual representation of the rules were posted and reinforced. Parents were encouraged to verbally state what was happening in the game and let children know when

transitions were to occur. To facilitate disengagement from the game, a visual schedule and timer were used to inform children of when their turns or the game were ending. Using a visual or timer takes the emphasis off of the parent's control and reduces the risk of argument. Limited choices do the same by allowing a sense of control for the child though in reality it is the parent who decides what choices from which a child may select. As in Ferguson and colleagues' intervention which used behavior skills training and Nintendo's Wii to teach sportsmanship skills, the therapist took on a teacher role helping to shape pro-social behavior (2013). For instance, encouragement was taught by operationally defining it for the children, providing examples of things to say such as "good game" and "nice try," practicing it, and then using it in the context of the game. Both therapist and parent modeled the behavior, reinforcing it with praise and a token economy system. Toward the end of the module, the therapist gradually faded probes and let the parent take over behavior management.

The program targeted prosocial behavior, self-control, and promoting a healthy family interaction. Specifically, therapists worked with parents to reinforce behaviors including sharing, turn-taking, body orientation, personal space, aggression, and conversation skills. In addition to working toward these explicit goals, therapists worked with parents to enable more subtle positive interactions with their children. For instance, it was important not to force children's participation but to determine why they are reluctant to participate

without drawing too much attention to negative behaviors. Thus, the child is not threatened by having control taken away in what could be an uncomfortable situation, sees the parent as an ally, but at the same time the parent is able to manage the situation. Parents used phrases such as “you do not have to play right now but you must sit in this chair and not interrupt the people who are playing,” therefore respecting the child’s wishes but still establishing rules and the importance of the family interaction. Therapists worked toward to goal of increasing positive family interaction rather than improving game performance and guided parents and children without overcorrecting, teaching parents to do the same. For example, during dance games parents were instructed to focus only on three dance moves to and verbally and physically prompt child only for these 3 instead of throughout the entire song. Doing otherwise could have been perceived as discouraging especially for children who experience motor planning difficulties. Using this strategy, the parent helped the child become successful at the game and the child had an opportunity to feel efficacious. The focus throughout was on the interaction between family members and not on the goals of the game with behaviors and successes reinforced accordingly.

Complete information for running the program is available in a manual created by the original researcher as part of a grant through the Autism Program of Illinois. The manual includes a general program overview, tips and pictures for how to set up the room, how to use the video games to support therapeutic goals,

suggestions for incorporating behavioral interventions and how to encourage a positive family interaction. It also includes tips based on the pilot study and information for working with children with autism (Gonzalez, 2011).

The format of the intervention allows parents to practice behavior management techniques while engaging in an activity that is not only enjoyable but one in which children often have some competency or skills. As opposed to various other interventions which focus on the children's deficits, the proposed intervention focuses on spending time together and promoting pro-social behaviors. Behavior management occurs only as necessary for all family members to successfully participate in the interaction. Furthermore, as an activity that can be replicated at home, there is a large potential for practice and generalizability in other settings.

### **Participants**

The 11 participants in the pilot program were originally recruited through a support group specifically for Latino families with children with autism. This group was associated with a Midwestern University autism clinic which provided the majority of referrals. The clinic provides services including psychological and speech evaluations, group and individual therapy, as well as social skills and art therapy. As a training center for the Autism Program of Illinois (TAP), the clinic also participates in research, professional development, and workshops as well as



providing clinical services. Through their participation in the TAP program all of the families had already received 16 hours of parent education classes in small group and individualized format provided by bilingual clinicians including psychologists, social workers, and speech therapists at the Hispanic autism clinic. Participants had also gone through the diagnostic process at the clinic which consisted of behavior observations, interviews with parents and a battery of tests that included an ADOS, intelligence testing, achievement testing as appropriate, and a language evaluation.

The clinic founded one of the largest support groups for families of children with autism with over 250 families enrolled and an average of 50 families participating in the monthly meetings. It is the only support group of its kind with its focus on Latino families and its structure that includes programming for all members of the family. All participants were enrolled in the support group which was formatted into presentations and workshops for parents, social group for teens, and process group for siblings, and art programs for children including music, art, and Mexican folkloric dance classes. In addition there are separate moms groups that meet regularly. Membership for the family support group is \$20.00 per family but is waived if the family cannot afford it. All services and presentations are provided in Spanish and the group runs largely by staff from the clinic, and a board comprised of parents with clinicians serving as advisors, and volunteers.

Participants volunteered for the program provided they met the inclusion criteria. In addition to being the biological parent of a child with an autism spectrum diagnosis, the families participating had the child living in their home and were the primary care-takers. To create a more homogenous sample, limitations with regard family composition were made a part of the inclusion criteria and only intact families with more than one child living in the home were allowed to participate. Although participation of both parents was strongly encouraged, mothers attended sessions more consistently than fathers. Overall, due to attrition rates, the final sample analyzed in this study was comprised of seven mothers and four fathers. The initial sample had an equal number of parents of each gender for a total of 16 parents. The sample unintentionally included only parents of male children with autism reflecting prevalence trends which show more males diagnosed than females.

Although data was collected for an even number of fathers and mothers, due to attrition, post-testing was only possible with part of the sample which included seven mothers (64%) and four fathers (36%). All of the parents identified as Latino and were first generation immigrants who originated from either Mexico (64%) or Guatemala (36%). All the parents identified Spanish as their primary language and their children varied with regard to dominant language between English and Spanish. All of the parents had male children with autism and at least one other child living in the home. The children with autism were

between the ages of 5-9 ( $M= 7.09$ ,  $SD=1.51$ ) and the total number of children per family ranged from 2-4 ( $M=2.5$ ,  $SD=.82$ ). Each family unit had at least one child with autism though, though two of the families had two children diagnosed with autism.

Information was collected regarding the family's use of electronic media and recreation as these were central to the pilot intervention. Seventy-five percent of parents reported owning a gaming console prior to the intervention and while parents reported their children spent an average of 1-2 hours playing video games at home ( $M=1.68$ ,  $SD=2.11$ , range: 0-3.5), only one parent reported ever playing video games with their child. However, for the most parents reported engaging in other family recreational pursuits though some admitted it was difficult to dedicate time to engaging with the family as a whole. Thus, there was much variability with regard to the time spent on family recreation with reports ranging from no time to six hours a week ( $M=1.4$ ,  $SD=1.9$ ). Family activities included playing in the park, reading, and playing sports activities like riding a bike. Frequency demographics for participant characteristics and family recreation can be viewed in Table 1.

## **Measures**

Archival data were utilized for this study and was obtained from a password-protected database containing responses to the PSOC, FLIS, and

maladaptive index of the Vineland-II. Demographic information was obtained from an information sheet developed for the original study and included the age of child at diagnosis, language spoken at home, family status (intact family or single parent status), number and age of siblings, interventions in which child has previously participated, access to computer and gaming system, time spent using technology such as computer and gaming systems, time spent together as a family engaging in various activities. Each parent in a two-parent dyad filled out the questionnaire prior to and at the conclusion of participation in the program.

**Parental Sense of Competence Scale.** The Parental Sense of Competence Scale (PSOC) was used to measure perceived efficacy and satisfaction in parenting. The PSOC is a 17-item parent-report 6-point Likert scale developed to measure the perceived degree of parental competence individual's experience. The total range for possible responses is 17-102. The scale is comprised of two subscales, Efficacy (scores ranging from 7 to 42) and Satisfaction (scores ranging from 9 to 54). The satisfaction scale, comprised of nine items, assesses enjoyment, motivation, satisfaction and fulfillment in the parenting role while the efficacy scale, comprised of seven items, assesses for perceived knowledge, confidence, control, and competence in parenting. Higher scores on the PSOC indicate greater parenting self-esteem (Johnston & Mash, 1989; Ohan, Leung, & Johnston, 2000).

Initially developed by Gibaud-Wallston and Wandersman in 1978 to be used with infants, the original scale measured Skill Knowledge and Value Comforting as two aspects of parental competence. The PSOC was later adapted by Johnston and Mash (1989) for use with parents of children ages 4 to 9 and validated using a normative sample of mothers and fathers. Johnston and Mash also separated and named the two factors of competence as Efficacy and Satisfaction. In 2008, the scale was provided with further evidence for validity, an additional factor, Interest, added, and the scale was normed to be used for parents of children up to the age of eighteen (Gilmore & Cuskelly, 2008). An original normative sample does not exist but Gilmore and Cuskelly developed a factor structure using a normative sample in 2008 which focused on the three factor model as opposed to Johnston and Mash's more common two factor model. Using this sample, total means for mothers were found to be 60.92 (SD: 8.94) and 60.62 (SD: 9.27) for fathers (2008).

The PSOC has an internal consistency of alpha .79 for the total score, .75 for the satisfaction score, and .76 for the efficacy score. Test-retest reliability had correlations ranging from .46 to .82. Construct validity has been found for both Efficacy and Satisfaction demonstrating that these factors are separate factors independent of each other. Items 1, 6, 7, 10, 11, 13, 15 are loaded on the Efficacy scale whereas items 2, 3, 4, 5, 8, 9, 12, 14, 16 are loaded on the Satisfaction scale (Ohan et al., 2000). Although the measure has 17 items, the 17<sup>th</sup> item is often

omitted as it does not load on any factor in the analysis reported by Johnston and Mash (1989). An analysis of the factor structure using a normative sample samples over 1200 participants allowing for separate factor analyses for mothers and fathers of children of a wider variety of ages (Ohan et al., 2000). However, despite this more recent information, since most of the reviewed literature referred to the version developed by Johnston and Mash, this was the version used for this study.

**Family Life Impairment Scale.** Perceived level of family impairment was measured with the Family Life Impairment Scale (FLIS). The FLIS (Briggs-Gowan & Carter, 2010) is a 36 item, multidimensional self-report measure used to assess the perceived level of impairment experienced by families with children with disabilities. The measure uses a scale of 0-2 allowing parents to indicate whether statements are “Not True” “Somewhat True” or “Very True.” In the cases where parents select “Not Applicable” a rating of one was used. All statements begin with “Because of my child’s behavior, personality, or special needs, we rarely...” The sum of possible scores yields a Global Impairment score that may range from 0 to 72. Higher scores are indicative of greater levels of impairment while lower scores reflect lower levels of perceived impairment.

The measure includes questions pertaining to family activities such as (“We rarely take him or her out to a family restaurant”), parent activities (“I am

UNABLE to see or talk to my relatives or friends as much as I would like”), childcare (“we RARELY leave him/her with relatives whom s/he knows well”), and positive growth (I have become more spiritual or religious.).

The FLIS helps examine the extent to which parents view their child’s behavior, personality and special needs as limiting or negatively affecting the parent. All items on the FLIS begin with the prompt “Because of my child’s behavior, personality, or special needs, we rarely. . .” Psychometrically, the FLIS has an acceptable internal consistency (Cronbach’s alpha = 0.80-.85), with item loadings ranging between 0.33-0.62 and a 10 – 45-day test-retest reliability of .70. Mean scores for the original sample were 26.4 with a standard deviation of 8.14. An independent clinical validation found the overall model fit was good (RMSEA = .042, CFI = .942.). Standardized factor loadings were between .36 and .91 and all loadings were statistically significant ( $p < .001$ ) (Mian et al., 2012).

**Vineland Adaptive Behavior Scales –II.** Maladaptive behavior for each child participant were measured using the Maladaptive Behavior Index of the Vineland Adaptive Behavior Scales, Second Edition, Survey-Interview Form in Spanish (Vineland-II) (Sparrow, Cicchetti, & Balla, 2005). The Vineland-II is a valid and reliable and individually administered instrument that is administered by the parent to measure adaptive behavior in individuals from birth to 90 years old. Standard scores are obtained to describe overall functioning (Adaptive Behavior

Composite) as well as standard scores for all three subtests: Communication (e.g., receptive and expressive skills including making requests), Socialization (e.g., playing with others, understanding humor), and Daily Living Skills (e.g., dressing, hygiene, household tasks). The Maladaptive Skills section describes inappropriate or undesirable behaviors and a high score reflects poor levels of adaptation. An additional Motor Skills section is also used for children under the age of seven. Given the variance in ages of the children in the present study, that scale has been omitted from analysis.

Administration takes 30-60 minutes and is conducted in a semi-structured interview with a caregiver, typically a parent who is familiar with the everyday activities and behavior of the individual being assessed. Responses are recorded by a trained clinician and converted into standard scores with a mean of 100 and a standard deviation of 15 with high scores reflecting better adaptive functioning. Scores correspond to developmental levels and age equivalencies to allow for comparison with peers and determine rates of delay.

The Vineland-II was normed using a control population as well as a population with autism spectrum disorders and is widely used as an effective assessment tool for determining levels of functioning across a wide array of domains (Sparrow et al., 2005). Using this scale with its parent-response format allows for some subjectivity but when administered in interview format by trained



professionals allows for a high sensitivity and specificity in determining developmental delays. To determine internal consistency, a split-half reliability test as used to examine the reliability of scores for the two halves of the test using the standardization sample data. To determine the correlations of the domains and subdomains across age groups the spearman-brown formula was used and resulted in correlations between .77-.93 for all three domains. The Adaptive Behavior Composite reliability was determined using the formula from Nunnally (1978) and correlations for this composite ranged from .93-.97 across age groups. Test-retest reliability was evaluated for stability over time by having a sample of 414 respondents from the standardization sample complete two forms of the Vineland-II on separate occasions within 2 weeks to one month of the first administration. Average correlations for all three main domains ranged between .76 and .92. Inter-interviewer and inter-rater reliability across sub-domains were both established at .70-.76 and .71-.81 respectively. A notable exception to the above was the Maladaptive Behavior Subscales, which consistently was found to have a much wider average correlation range, still congruent with the above findings, but with a higher average degree of correlation (“Review of the Vineland”, 2011).

This study looks specifically at parent reports of their children’s functioning on the Maladaptive Behavior Index on the Vineland –II, used to measure the level of negative child behaviors, is comprised of an internalizing

scale, externalizing scale and additional sections labeled “other” and “critical items.” Items are answered “never,” “sometimes,” or “usually” and are scored as 0, 1, and 2 respectively. Scores are transformed into v-scaled scores with higher scores considered to be indicative of greater behavior problems. Each scaled score also corresponds to categories ranging from average (1-17), elevated (18-20), and clinically significant (21-24) (Sparrow et al., 2005).

### **Procedures**

This researcher utilized archival data gathered in the pilot program to assess the effectiveness of this novel intervention program with Latino families and whether working toward these goals would have effects on parental competence and family functioning and to the degree that maladaptive behaviors would interfere with these. Only the de-identified database was used for the purpose of this study. The researcher submitted and had the research approved by the Institutional Review Board at the Adler School of Professional Psychology (see Appendix 1). As an archival study, no informed consent beyond that to initially participate in the study was required. Permission was obtained from the owner of the data set and care was taken to maintain data security. Because in many cases only one parent attended the treatment sessions, the results of the other parent were not analyzed. Beyond this, the data set was used in its entirety.

## **Chapter IV**

### **Results**

A pre-post (repeated measures) design using a two-tailed was used to answer the first research question which asked if perception of parental competence would improve after participating in the program. Separate t-tests were conducted to examine each of the two subscales of the PSOC (parent satisfaction and parent self-efficacy) to determine whether either of the two were more affected. A two-tailed t-test was used to answer the second research question which predicted that the level of perceived family impairment would decrease following participation in the program. The third research question asked if any relationships would exist between the incidence of maladaptive behaviors, parental competency and family impairment. To examine this, a Pearson's correlation test was used to determine if a significant inter-relationship exists between family impairment or parental competence and children's maladaptive behavior. Finally, the fourth research question asked if differences in one parent and two parent groups existed was tested using independent t-tests.

Paired sample t-tests were utilized to examine the differences in parental competence and family impairment at pre and post-testing. A correlation analysis was used to determine whether significant relationships between parental competence, family impairment and child maladaptive behavior existed. Finally,

independent t-tests and a chi-square analysis was run to examine differences in parental competence and family impairment in groups where one parent versus two parents parent participating.

### **Descriptive Statistics**

At pre-testing, the average PSOC score was 42.72 with a standard deviation of 5.75. The minimum individual score was 34 while the highest individual score was 52. Seven of the eleven scores were within one standard deviation of the mean while the remaining four were within two standard deviations of the mean. At post-testing, the average score was 48.27 with a standard deviation of 9.17. The minimum individual score was 35 whereas the maximum individual score was 64. All but one score was within one standard deviation of the mean. An examination of individual scores revealed that eight of the eleven participants improved in parental competence. Of the three participants who did not show improvement, two had scores that were nearly identical, reflecting no real change whereas only one remained higher at pre-testing than post-testing. A visual representation of the individual scores can be seen in Figure 1.

At pre-testing, the average FLIS score was 32.27 with a standard deviation of 12.69. The minimum individual scores was 5 whereas the maximum individual score was 49. All but three scores were within one standard deviation of the mean.

At post-testing, the average FLIS score was average FLIS score was 30.36 with a standard deviation of 8.89. The minimum individual scores was 17 whereas the maximum individual score was 45. The scores had variability with six scores within one standard deviation and five scores within two standard deviations. Altogether, family impairment was higher for 7 of the individuals at pre-testing. For the remaining 4, 3 showed lower levels of impairment at pre-testing whereas one demonstrated no change. See Figure 2 for a visual representation of scores.

On average, the scaled score for the maladaptive behavior index of the Vineland-II was within the Elevated range of functioning ( $M=19.73$ ,  $SD=1.68$ , range: 18-23). Overall, all of the parents but one indicated that their child was functioning in either the elevated or clinically significant range of functioning. Only one parent indicated that their child was within the average range of functioning with regard to maladaptive behaviors. All but one of the respondents indicated that their child was experiencing significantly higher internalizing problems than externalizing problems. In fact, the difference in all of these cases was sufficient that the scores fell into separate categories. In the case of the only exception, parents indicated clinically significant scores across the board for internalizing and externalizing problems. Means and standard deviations for all measures can be found on Table 2 in addition to the normative means for comparison where available.

### **Parental Competency and Family Impairment at Pre and Post Testing**

The first hypotheses predicted that parent's perception of parental competence would increase following parental participation in the pilot intervention program. A paired-samples t-test was conducted to compare parental competency before and after participation in the pilot intervention program. There was a significant difference in parental competency scores at pre-testing ( $M=42.73$ ,  $SD=5.75$ , range: 34-52) and post-testing ( $M=48.27$ ,  $SD=9.17$ , range: 35-39);  $t(10) = -2.67$ ,  $p < .05$ ,  $d = .72$ , moderate to large effect. These results suggest that following participation in the program, parents experienced an increased perception of parental competence.

To further examine whether either efficacy or satisfaction, the two components that make up competency, were more strongly affected, each of the subscales was analyzed separately using two-tailed t-tests. There was a significant group difference in parental self-efficacy at pre-testing ( $M=15.64$ ,  $SD=3.01$ , range: 11-19) and post-testing ( $M=20.36$ ,  $SD=5.68$ , range: 12-30);  $t(10) = -4.188$ ,  $p < .05$ . Paired t-tests on parental satisfaction also found a significant group difference at pre-testing ( $M=23$ ,  $SD=4.34$ , range: 15-28) and post-testing ( $M=26.27$ ,  $SD=7.07$ , range: 15-36);  $t(10) = -2.402$ ,  $p < 0.05$ . These results suggest that following participation in the program, parents experienced increases in both parental efficacy and parental satisfaction.

The second hypotheses predicted that parent's perception of family impairment would decrease following parental participation in the pilot intervention program. A paired-samples t-test was conducted to compare family impairment before and after participation in the pilot intervention program. There was no significant difference in family impairment scores at pre-testing ( $M=32.27$ ,  $SD=12.69$ , range: 5-49) and post-testing ( $M=30.36$ ,  $SD=8.89$ , range: 17-45);  $t(10) = 1.08$ ,  $p > 0.05$ . The results for paired t-tests for parental competency and family impairment are shown in Table 3.

### **Correlational Analysis for PSOC and FLIS and the Maladaptive Behavior**

#### **Index**

Pearson product-moment correlation coefficients were computed to assess the relationship between parental competence, family impairment, and children's maladaptive behavior. There were no significant correlations between any variables at pre-testing. However, no significant correlations were found to exist between any variable and the maladaptive behavior scale on the Vineland II. Results are summarized in Table 4.

### **Comparison Based on Number of Parents Participating in the Intervention**

An independent-samples t-test was conducted to compare parental competence at post-testing in families where one parent participated ( $M = 44.75$ ,

SD = 5.25) and families where two parents participated (M = 50.29, SD = 10.64). There were no significant differences in parental competence based on the number of parents participating;  $t(9) = -.06, p > .05$ . These results suggest that parents did not experience differing levels of parental competence in groups when one versus two parents participated.

An independent-samples t-test was conducted to compare family impairment at post-testing in families where one parent participated and families where two parents participated. There was a significant difference in family impairment for families where one parent participated (M = 23.25, SD = 6.13) and two parents participated (M = 34.43, SD = 7.74);  $t(9) = -2.46, p < .05$ . These results suggest that groups where two parents participated experienced a higher level of impairment than groups where one parent participated. Results of Independent t-tests are summarized in Table 5. Altogether the results of the independent t-tests demonstrate that there were indeed differences when one parents versus two participated.

At the conclusion of the program, all of the parents reported that they had begun to play video games at home with their children. Of the parents who did not previously own a gaming console, all stated they were interested in purchasing one in order to have an activity for exercise in the winter and to play as a family.



All of the participants reported enjoying the activity and the children especially were motivated to attend sessions.

## **Chapter V**

### **Discussion**

The purpose of this study was to determine whether parents of children with autism would experience increased parental competence and decreased family impairment following participation in a pilot intervention program in which behavioral supports were taught while the family played video games. This study is among the first to investigate the effects of family functioning and recreation where video games were used to structure the interaction.

#### **Explanation of results**

The results from the current study indicated that parents of children with autism who participated in the pilot intervention program experienced increased parental competence at the conclusion of the program. It is possible that engaging in a positive experience with the overall focus on fun and recreation created an environment where children were more receptive to behavioral change. Especially for those parents who admitted to spending very little time engaging in recreational pursuits, the program may have provided an outlet to connect with their children. Given that most of the children had some experience with video games whereas parents did not, it may have also allowed parents an opportunity to witness their child succeed and in some cases show mastery of an activity—an experience they may not often experience in other settings. While the goal of the program was to increase child-prosocial behavior and parent perception of family

functioning, the approach toward behavioral change was subtle and embedded within the children's play making it more generalizable to natural family settings.

While no significant effects were found from pre to post test on the family life impairment scale, there were also no negative effects. If anything, the content does no harm and may encourage families to engage in recreational pursuits as a family increasing opportunities for family bonding and greater cohesion at a later point in time.

Parental competence and family life impairment were positively correlated indicating that as competency rose, impairment increased. It is not clear what contributed to this finding but the findings with regard to family life impairment were complex and may suggest that family impairment may depend in part on the number of parents participating and the dynamic between the two parents. In fact, families where two parents participated demonstrated greater impairment than families in which only one parent participated. This is an important finding as the literature has focused on the trends indicating it is usually mothers who participate in treatment, and have sought to include fathers as well but no research was found on the effects of having both parents participate. Although on the individual level, parental competency rose, it is possible that increases across couples or that discrepancies between parents may have contributed to greater impairment. Furthermore, the measure used to assess family impairment reviews family functioning broadly assessing spirituality, relationship between parents, and ease

of child-care among other factors which may not have been addressed in the short duration and limited focus of the program.

While it is unrealistic to expect major lifestyle changes given the time limited nature of the intervention it is noteworthy that all participants indicated a positive, though not statistically significant change. When asked if they would recommend the program to other families, all participants responded "yes."

### **Alternate Explanations**

There may also be other explanations for the above findings. Another explanation for why parental responses on the FLIS did not significantly change following participation in the program may have to do with baseline effects. All of the parents who participated in this study were part of a broader support group for families with children on the spectrum and had been members for some years and engaged in and received varying levels of support aimed at increasing child skills as well as reducing parental stress. All families in this study have children with autism and it is unlikely that family functioning will ever be perceived as having no difficulties. However, it is possible that at the onset of intervention, families had already received supports to reduce their levels of family impairment to a point which was satisfactory. Previous studies have shown that families such as those that participated in this study expressed satisfaction with their current levels of family functioning. In a study by Altieri and Kluge, for example, parents of children with autism reported feeling satisfied with their current level of family

functioning which the researchers explained led to reduced statistical sensitivity in detecting small differences in behaviors (2009). Baseline effects may have significantly affected the possibility of change in family functioning and family impairment specifically.

Alternatively, there may have been little change due to the nature of autism as a permanent condition and a reflection of the long-standing effects of diagnosis and prognosis on the child and family. The mean score for the original sample was 26 and even in Lambert's 2012 administration of the FLIS to parents of children with autism, the mean did not differ significantly from the normative sample. With the current sample, a mean of 32 at pre-testing and a mean of 30 at post testing revealed a significantly greater level of impairment for the current population. It is not clear what it is that made this sample more impaired but possibilities include the fact that it was an entirely Latino, first-generation sample whose primary language was Spanish all of whom received services using the state's public aid. With the exception of the latter, the rest are marked differences from Lambert's sample and all of the characteristics described herein are a marked difference from the normative sample. The results suggest that Latino families are starting services facing a higher level of impairment that may require more intense interventions and culturally sensitive approaches. Although this scale was not effective for measuring change in the current study, it nonetheless provided useful information for measuring overall family impact. Addressing the

overall level of family impairment is an ongoing process whose stability is based on many external and systemic factors which cannot be addressed in a single intervention but whose effects should be assessed and studied to better understand the challenges of families facing challenges related to disabilities.

Previous research has suggested that families who at the onset of treatment have high levels of functioning and low impairment are less likely to show significant changes. Both Ben-Sasson and colleagues' and Keen and colleague's studies on stress and family functioning for instance showed no significant changes even when parenting interventions were specifically targeted (2013; 2010). In both studies parents who were doing well at the onset continued to do well whereas parents who reported poor levels of family functioning continued to experience reduced levels following treatment. It is possible that more research needs to be done to target the specific needs of these families who are experiencing poor levels of functioning as research has demonstrated that these families are less likely to benefit from equivalent treatment efforts compared to families whose functioning is relatively healthy (Sikora et al., 2013). Alternatively, it is possible that family functioning is difficult to markedly change as several studies have indicated relative stability in family functioning over time for families of children with autism even at the one and two year follow-up time. (Peters-Scheffer, Didden, & Korzilius, 2012). Notably, in this study as well as in previous research, parental competence was more susceptible to change and less

affected by baseline effects, adding further evidence that these are indeed two separate constructs. Overall, it is clear that future research on family functioning should include a discussion on how baseline effects.

There are other factors in addition to baseline effects that may have affected the results. The FLIS, though psychometrically sound, is not able to fully detect the subtle nuances of improved family functioning or was not a sensitive measure to the area being assessed. Therefore, while family functioning may have improved, families may have been experiencing stress from other areas of functioning that affected negatively the family. It is also possible that the intervention simply did not work as was intended to reduce parenting stress. Previous research found that some parents, fathers in particular, used avoidance as a coping mechanism to guard against the stress of raising a child with autism (Bristol et al. 1993; Gray, 2003; Hastings et al, 2005; Rodrigue et al., 1990). The format of the intervention took away this coping mechanism forcing parents into interactions for which some parents may not have felt prepared. Spending increased time together and the need to address behavior problems may have contributed to the stress experienced by some parents. Furthermore, although video games were chosen as a recreational outlet with potential for enjoyment and stress, given that most parents admitted being unfamiliar with video games, it is possible that engaging in a new and challenging activity while actively addressing their child's behavior was perceived as a stressful activity. Future interventions

focused on family interaction might utilize a recreational activity that is engaging but familiar.

There are many variables outside of having a child with autism that may have contributed to overall stress levels of the participants. In one study on maternal well-being, researchers found that mothers with better socio-economic status reported higher levels of well-being when compared to mothers with low income levels regardless of the level of disability of their family member (Eisenhower & Blacher, 2006). Parents with more financial resources are more likely to have insurance, have access to a greater number of treatment options, and their children have more opportunities to be identified earlier on with a disability as they are more likely to attend pre-school. Although data on finances was not collected for the existing study, all of the participants identified as immigrants for whom the poverty level is 49% with Mexican immigrants facing a poverty level of 69% compared to American-born families for whom the poverty level is 34% (Hernandez, 2004). Additionally family income and the number of children per family has been found to contribute significantly to the quality of life reported by parents which is consistent with findings that affluent families of children with autism report lower levels of distress (Bromley, Hare, Davison, & Emerson, 2004). Lastly, there are individual factors that may have contributed to the experience of stress and perceived family impairment. In one study, logistic regression models showed that although having a child with autism accounted for



a significant source of stress for mothers, poor expression of affect, little interest in people, being an older mother, and having a younger child also contributed to increased stress levels (Duarte, Bordin, Yazigi, Mooney, 2005).

### **Contributions to the Literature**

This study supports the existing data that family interventions can increase parental competence. Additionally, this study has contributed to the body of knowledge that currently exists on the role of family recreation on family functioning. The findings contribute to the understanding that family engagement in recreational pursuits may be a viable format for behavior interventions that may be more easily generalizable to natural family interactions. The findings also demonstrate complexities in how family functioning is affected by increases in parental competence and by the number of parents participating in an intervention. The positive correlation between parental competence and family impairment was unexpected as was the finding that families where two parents participated experienced higher levels of impairment. As prevalence rates for autism continue to rise so does the need to understand how to address the need of the child and family as a whole.

The reports of this study are consistent with previous literature on parental competency. For instance, this study supports a previous studies on parental competence including Gray's ten year study on family functioning and competency (2002). Gray found increased parental competence, associated with

positive coping mechanisms, helped reduce the effect of social isolation, stigma, rejection and lack of social supports. This study also supports the findings of a 2013 study which found participation in a family strengthening program, completed over a two to three month period during which parents participated in one session per week, significantly improved parental satisfaction and efficacy as measured by the PSOC. However, where that study demonstrated significant gains in family functioning as measured by the North Carolina Family Assessment Scale, the current research did not find significant changes in family impairment as measured by the FLIS (Katisikitis et al., 2013). In the current study, parental self-efficacy tended to be significantly lower with a mean of 20.36 post intervention contrary to self-efficacy scores in Johnston and Mash's normative sample (1989) and in Keen et al's 2010 sample which tended toward the mean ( $M = 25.60$ ) from pre to post intervention. This difference may have been an effect of the small sample size or the broader pool from which the sample was selected. This sample was comprised of parents who were all first generation immigrants, for whom English was not their dominant language, and who on average did not have more than a high school education, characteristics which may have negatively affected general self-efficacy.

Although parental competency rose post-intervention, it nonetheless remained below the normative mean which demonstrates that even though improvement is possible, families of children with autism have a lower baseline

for parental competency than families of typically developing children. Conceptually, this makes sense because competency is built from a collection of successful experiences. Families of children with autism face more challenges with the parenting experience and likely experience more discouragement regarding their role as parents which is then validated by external factors. This may explain why parents of children with autism experience greater distress than parents of children with other disabilities. The presentation is different and autism tends to result in more extreme behavior. The parent's difficulty managing the negative behaviors and the personal resources it takes to do this successfully may leave parents feeling less efficacious and less satisfied with their role as parents. This is not to say parents of children with autism don't find meaning in their roles as parents or that improvements cannot be made but a recognition that the greater challenges presented by autism call upon greater levels of energy, creativity, information, support, and resources to not only manage the child's behavior but the parents' understanding of the role, and societal expectations.

The findings add to the growing evidence of the importance of incorporating recreational pursuits into treatment for children with autism and including the family when possible. Enhancing positive family functioning hold great promise for reducing parental levels of stress making parents more available to participate in treatment. All too often, the focus of research has been on the relationship between caring for children with autism and parental stress with little

recognition to positive family functioning that occurs in spite of, or because of, having raised a child with a disability. Changing perceptions through positive family interactions may help reduce parental stress and increase positive family functioning. Engaging in positive family experiences and shifting perceptions has the dual benefit of serving as an adaptive coping mechanism for families (Hastings and Taunt, 2002). Interventions such as this which allow for behavior supports in vivo supports Hastings and Taunt's findings that professional support appears to be particularly effective in helping reframe child behavior to be viewed more positively rather than changing parent perceptions about the parenting role. Practicing skills in a supportive environment within a culturally responsive framework allows parents to experience success and motivates change.

The current research adds to the literature on the use of video games in treatment. Though video games have been used with children with autism, their use has been largely focused helping develop motor skills with limited research into their use for developing social skills. The potential for benefits in social skills extends beyond that which is practiced in session and used with the family. Given the popularity of video games, increased familiarity and proficiency with the video games and gaming system may provide children with subject matter for developmentally-appropriate conversation with peers and parents with a way to connect with their children. As discussed by Picard and Goodwin (2008), one limitation of many research interventions lies in the nature of delivering the

intervention in an unfamiliar clinic or lab where only a small sample of the participant's behavioral repertoire is used to characterize him or her. However, in the case of this program, the intervention is meant to be generalized into the home setting for continued participation in the natural home environment. Some researchers have cautioned that time spent engaging in video game play is negatively related to time spent in social interactions or exercise (Sisson, Broyles, Baker, & Katzmarzyk, 2010). However, the current study tried to account for that by using only games that required some degree of social interaction or turn taking and physical activity.

Beyond the effects on socialization, Lieberman briefly explored video game's potential benefits on self-efficacy (2006). She noted the emphasis on vicarious experiences is designed to increase player's self-efficacy by providing tasks at increasingly levels of difficulty which allows players to experience increasing success. Although the success is initially based on game-related outcomes, studies have shown that video game play can also have positive effects for gaining specific skills. In the case of child management, though playing the game does not necessarily improve parenting skills, it does provide an avenue through which parents may direct pro-social child behavior through an external means (the gaming console). The enjoyment from the whole family, health benefits, and improvements in pro-social behavior encouraged several of the

participants to later purchase the games to continue to practice playing as a family at home thereby generalizing skills and continuing to maintain gains.

### **Limitations**

One main limitation is that the sample of participants was small. This was expected as studies on families with children with autism tend to be small (Altiere & Kluge, 2009), however the current sample was also affected by the relatively small pool to draw from and the limitations created by exclusion criteria. Despite its small sample size, the research resulted in some significant findings.

Previous studies both by experienced researchers and graduate students have used small samples and had significant findings, even when these did not occur at the statistically significant level. For instance, in Lopez's 2013 dissertation study, which like in the current study, Latina mothers of children with autism participated in an intervention held over an eight-session module, post data revealed positive effects on all of the target domains. One major difference however was that the program was educational in nature and focused specifically on increasing parents' knowledge on services, advocacy skills, and strategies to work with their children. The current study on the other hand focused on the entire family and did not measure knowledge but perceptions of family functioning which may be more difficult to change. A review of the literature found other published studies with small samples. Among these were Garza and

his fellow researchers' qualitative evaluation of a similar program that encouraged positive interactions with children found gains and useful information despite a sample of only seven participants (2009) and Shu and Lung's quasi experimental pre-post support group spanning 10 weeks and including only eight mothers in the experimental group (2005). Two of the most cited studies in the literature, Gray's longitudinal study (2002) and Altieri and Kluge's study (2009) also yielded significant and widely cited results despite having less than 30 participants.

A review of the literature found few large studies but even then the largest sample sizes tended to include on average about 30 participants or in general no more than 75 participants. Few samples included over 100 participants (Greenberg et al., 2004; Shur-Fen Gau et al, 2012; Sikora et al., 2013). A notable exception was Myers and colleagues 2009 study which included almost 500 parents from six different countries including the U.S. However, this study required only online completion of a survey with no intervention, measures, or active participation needed and participants were recruited from over 200 autism-related organizations. Overall, the limitations in sample size may have limited the potential for results within the study and limits the extent to which the results are generalizable in the greater population.

The findings are limited as well by sample characteristics including the sampling pool, gender, and inclusion criteria. Participating families had all

received psycho-education and treatment at a clinic specializing in children with autism which is not representative of the full range of experiences of children with autism. Given that this sample was recruited from a family support group geared toward Latino families of children with autism, it may be assumed that these families may experience less impairment or already have supports to address this in place. Furthermore, because they volunteered for participation, it is possible that they already had high levels of connectivity with services and the commitment to seeking supplemental services for their children.

Although inclusion criteria limited the participants to intact families with both a mother and father being willing to participate, ultimately, in many cases fathers dropped out of the study thus limiting the available data and the possibility of comparing results across genders. This gender bias is not unusual as research shows that Latino men may be less likely to participate in child-rearing including when there is a child with a disability in the family and that a common coping mechanisms for this group is to withdraw from the family (Moreno, 1995). Although the current investigation focused on the experiences of parents, and not the children specifically, it is possible that experiences of parenting male children with autism differs from parenting female children with autism. All of the participants were the parents of male children with autism with no parents of girls represented. However, this reflects prevalence rates which show that boys are



diagnosed with autism more frequently than girls (Centers for Disease Control and Prevention, 2014).

This study, like most of the studies in the literature focused primarily on the experiences of mothers of children with autism. A review of studies on child psychopathology revealed that 48% of the studies assesses mothers exclusively while only 1% assessed fathers (Cassano, Adrian, Veits, & Zeman 2006). Though attempts were made to include fathers in this study, going so far as to make intact heterosexual families part of the inclusion criteria, due to conflicts with scheduling, fathers were not able to consistently attend sessions.

The generalizability of the findings is limited by the lack of control group. No comparisons have been done between this group and a group of parents who received different interventions or no intervention at all. Thus, there is no way of knowing whether the changes in parental competence may be attributed to participation in this program or are the result of other outside factors.

This study like the majority of studies in the parenting literature relied on self-report measures. A concern with self-report data is that the participants may provide answers they view as correct or a desire to please the examiner by providing what they view to be as a preferable response. In order to minimize pressure to please the examiner post-testing measures whenever possible were distributed by a different individual than those who conducted the sessions and were placed in an envelope rather than handed to the researcher. Self-report

measures for parenting experiences tended to have a greater focus on negative experiences whereas open ended interviews allow for parents to elaborate on the positive growth and associations to raising a child with a disability. With regard to the measures used within in this study, although the PSOC is one of the most widely used measures to assess parental competence and efficacy, there nos no normative group for comparison (Gilmore & Cuskelly, 2008). The FLIS on the other hand is a newer measure and while its internal consistency reliability was strong and preliminary factor analysis supported the factor structure, further studies of the tool's validity are needed. One last limitation of the measures used in this study is that neither the Parental Sense of Competence Scale nor the FLIS have been standardized on bilingual Spanish-speaking populations and in fact, both were translated specifically for this using the back translation method. An additional limitation was the inclusion of the Maladaptive Behavior Index of the Vineland-II scale. This measure was selected as part of the regular battery administered to children at the clinic where the intervention took place. Although the Vineland-II is considered a good measure for adaptive behavior, the Maladaptive Behavior Index has a wider correlation range than the other scales ("Review of the Vineland," 2011). Furthermore, the nature of the sample which included only children with autism who were all in the elevated range with only one example did not allow for much variability. Having a homogenous sample did not allow this measure to fully capture changes in behavior. In retrospect, it would

not have been the best measure to use. Future studies might emphasize the measurement of pro-social behaviors during play interactions as these were the focus of the intervention. A promising alternative to measure these might be the ADOS as used by Lindley and colleagues in their 2008 study where used the measure to code social-communicative behavior, gestures, and utterances during video game play with female undergraduates. This would allow not only a more detailed look at both adaptive and maladaptive social behaviors, but would allow researchers to compare information with that at diagnosis. Of course, the context would be different and so progress could not be tracked in this way, but used simply to compare information qualitatively

### **Future Directions**

The current investigation and research behind it demonstrate that parents of children with autism clearly face increased levels of stress. This is not only an area worthy of further study not only because of the needs of the parents but because parents who are experiencing extreme levels of stress may not be able to adequately engage in treatment. Implications for practitioners include a need to assess parents' stress levels and feeling of parenting competence in order to meet the parents' needs where they are at. Assuming that all parents are ready to engage fully in treatment may delay or impede carryover and maintenance of gains in the home setting. Several authors in the reviewed literature recommended assessing parental well-being as part of the treatment plan before implementing

any parenting intervention and to address symptoms of stress and depression, in order to maximize intervention outcome (Kuhn & Carter, 2006; Rao & Beidel, 2009). Doing otherwise may result in stress and depressive symptoms interfering with the parent's ability to engage in interventions with her child. Establishing a baseline will also help guide goals and expectations.

Despite evidence of the stress experienced by parents of children with autism few interventions exist to address the parental stress outside of support groups, even less exist in a way that addresses the core symptoms of autism while simultaneously relieving stress for the entire family. The current investigation addresses family functioning in a way that is fun for the family while building pro-social and adaptive behaviors and increasing parental competence. Furthermore, it does so in a way using conventional and socially acceptable means –important for a population whose culture often associates therapy with shame and stigma (Magaña & Smith, 2006).

Given the importance of the family and the bidirectional influence between parent and child, future research should continue to assess how autism affects the family as a whole and include families in treatment where possible. When parents take an active role in developing and implementing interventions by mutually agreeing upon goals, sharing expertise and responsibility, collaborating on problem solving and using a strength-based approach that fits with cultural values, they are more likely to actively participate and generalize skills into the home

setting (Brookman-Fraze, 2004). A review of parent participation programs found that a critical piece to program success has been to devote attention and resources to overcoming participation barriers such as transportation, using home visits or incentives, and maintaining contact with participants regardless of their rate of participation (Lee, August, Bloomquist, Mathy & Realmuto, 2006). Keeping this in mind when building programs for Latinos will help build retention rates and help parents feel supported, especially considering the additional barriers faced by Latino families, the importance the culture places on warm relationships, and the multiple stressors faced by families of children with autism. Family centered approaches such as the current study may help emphasize the importance of strengthening family functioning (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009).

The current study included siblings but did not assess their feelings toward their brother or sister, skills, or any other area of functioning. Future studies can expand on the current research by evaluating how sibling participation in interventions affect not only skill acquisition but family cohesion. Sikora et al. found that children's externalizing behavior problems are not only negatively associated with parental well-being, but with that of siblings as well (2013). The literature on siblings has shown both positive and negative effects but there is little research on what contributes to each state. Furthermore, while there is extensive research on the role of parents and peers in treatment approaches, there

is little research on the efficacy of siblings' participation in treatment for children with autism. However, the literature shows that including siblings in treatment has positive effects on the sibling's satisfaction with the relationship and increases engagement for both children (Ferraioli, Hansford, & Harris, 2011). Including siblings in behavioral interventions has been documented to be beneficial to both children, and promotes the generalizing of learned skills for the sibling with ASD. Though sibling relationships include both play and the resolution of conflict and rivalry, the ratio for families with children with ASD skew toward the latter. Increasing the number of positive interactions results in benefits beyond the sibling relationship and extending to the entire family dynamic. Future studies could focus on the effects of participation in such an intervention for neuro-typical siblings of children with autism both on siblings and on the parents. Spending time together might be the key. Future studies can continue to further explore how spending time as a family may bring increased cohesiveness

Overall, this is one of the first studies to examine the role of family recreation using video games in a family group with behavioral supports. Findings highlight the importance of including the whole family in interventions and providing a positive environment for change. Despite the small sample size, findings suggest that the experience of success in guiding their children and the focus on family fun resulted in an increase in parental competence. Children interviewed after their program expressed satisfaction with their participation,

particularly seeing their parents engage in silliness, exercising, and playing as a whole family. Parents expressed satisfaction about the behavioral change and increased control demonstrated by their children following the behavioral intervention. One parent explained “*“I think he controls himself more now. Before when he threw a tantrum we would run to stop him. But he is stopping himself now and then joining the family to play”*” while another said “*“I like how we spent time together and how we’ll have something to talk about and plan for next time.”*” Both parents and children expressed interest in participating in similar interventions in the future. Understanding how to building parental competence may serve to decrease the stress experienced by families of children with autism and create a more positive parenting experience.

## References

- Abidin, R.R. (1977). Parenting Skills. *Psychology in the Schools, 14*(12), 239-240. doi:10.1037/t02445-000
- Altiere, M. J., & Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies, 18*(1), 83–92. doi:10.1007/s10826-008-9209-y.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. doi:10.1037/0033-295X.84.2.191
- Bandura, A. (1989). Regulation of cognitive processes through perceived self-efficacy. *Developmental Psychology, 25*(5), 729-735. doi: 10.1037/0012-1649.25.5.729.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York City, NY: Freeman.
- Bandura, A. (2004). Social cognitive theory for personal and social change by enabling media. In A. Singal, M.J. Cody, E.M. Rogers, & M. Sabido (Eds.), *Entertainment-education and social change: History, research, and practice* (pp.75-96). Mahwah, NJ: Erlbaums.



- Bettleheim B. *The empty fortress: Infantile autism and the birth of the self*. New York, NY: Free Press; 1967.
- Bickham, D.S., Vandewater, E.A., Huston, A.C., Lee, J.H., Caplovitz, A.G., & Wright, J.C (2003). Predictors of children's electronic media use: An examination of three ethnic groups, *Media Psychology*, 2, 107-137.  
doi:10.1207/S1532785XMEP0502\_1
- Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in Latina mothers with and without children with retardation: Implications for caregiving. *Family Relations*, 46(4), 325-334. doi:10.1111/j.1365-2788.2006.00913.x
- Bohon, S.A., Macpherson, H., & Atilas, J.H. (2005). Educational barriers for new Latinos in Georgia. *Journal of Latinos and Education*, 4(1), 43-58.  
doi:10.1207/s1532771xjle0401\_4
- Bower, G. H. (1981). Mood and memory. *American Psychologist*, 36(2), 129-148.  
doi: 10.1037/0003-066X.36.2.129
- Boyd, B. (2002) Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17, 208-215.  
doi:10.1177/10883576020170040301
- Boyd, B., Odom, S., Humphreys, B., & Sam, A. (2010). Infants and toddlers with autism spectrum disorders: Early identification and early intervention.

*Journal of Early Intervention*, 32(2), 75-98.

doi:10.1177/1053815110362690.

Brentani, H., Silvestre de Paula, C., Bordini, D., Rolim, R., Sato, F., Portolese, J. .

. McCracken, J. T. (2013). Autism spectrum disorders: An overview on diagnosis and treatment. *Revista Brasileira de Psiquiatria*, 35, S62–S72.

doi:10.1590/1516-4446-2013-S104

Briggs-Gowan, M.J. & Carter, A.S. (2010). *The Family Life Impairment Scale:*

*Version 3.0*. Unpublished measure: University of Connecticut Health Center and University of Massachusetts, Boston: MA.

Briggs-Gowan, M.J., Carter, A.S., Bosson-Heenan, B.A., Guyer, A.E. & Horwitz,

S.M. (2006). Are infant-toddler social-emotional and behavioral problems transient. *Journal of the American Academy of Child and Adolescent*

*Psychiatry* 45(7), 849-858. doi:10.1097/01.chi.0000220849.48650.59

Bristol, M. M., Gallagher, J. J., & Holt, K. D. (1993). Maternal depressive

symptoms in autism: Response to psychoeducational intervention.

*Rehabilitation Psychology*, 38, 3-10. doi:10.1037/h0080290

Bromley, J., Hare, D.J., Davison, K., & Emerson, E. (2004). Mothers supporting

children with autistic spectrum disorders: Social support, mental health status, and satisfaction, with services. *Autism*, 8(4), 409-423.

doi:10.1177/1362361304047224

- Brookman-Fraze, L. (2004). Using parent/clinician partnerships in a parent education program for children with autism. *Journal of Positive Behavioral Intervention, 6*(4), 195-121  
doi:10.1177/10983007040060040201
- Carter, A.S., Ben-Sasson, A. & Briggs-Gowan, M.J. (2011). Sensory over-responsivity, psychopathology, and family impairment in school-aged children. *Journal of the American Academy of Child and Adolescent Psychiatry, 50*(12), 1210-1219. doi: 10.1016/j.jaac.2011.09.010.
- Carter, A.S., Wagmiller, R.J., Gray, S.A.O., McCarthy, K.J., Horwitz, S.M. & Briggs-Gowan, M.J. (2010). Prevalence of DSM-IV disorder in a representative, healthy birth cohort, at school entry: Sociodemographic risks and social adaption, *Journal of American Academy of Child and Adolescent Psychiatry, 49*(7), 686-698. doi:10.1016/j.jaac.2010.03.018
- Cassano, M., Adrian, M., Veits, G., & Zeman, J. (2006): The inclusion of fathers in the empirical investigation of child psychopathology: An update, *Journal of Clinical Child & Adolescent Psychology, 35*(4), 583-589.  
doi: 10.1207/s15374424jccp3504\_10.
- Cecchi, V. (2005). *Los Otros Creen Que No Estoy: Autismo y Otras Psicosis Infantiles* (Spanish Edition). Buenos Aires, Argentina Lumen
- Centers for Disease Control and Prevention (2014) Prevalence of autism spectrum disorder among children aged 8 years – autism and developmental

disabilities monitoring network, 11 sites, United States, 2010, *Surveillance Summaries*, 63, 1-24.

Chiong, C. (2009). *Can Video Games Promote Intergenerational Play & Literacy Learning?* (Report from a Research and Design Workshop). Retrieved from The Joan Ganz Cooney Center website:  
[http://www.joanganzcooneycenter.org/wp-content/uploads/2010/03/intergen\\_final\\_021210.pdf](http://www.joanganzcooneycenter.org/wp-content/uploads/2010/03/intergen_final_021210.pdf).

Comas-Diaz, L. (1987) Feminist Therapy with Mainland Puerto Rican Women. *Psychology of Women Quarterly*, 11(4), 461-467. doi:10.1111/j.1471-6402.1987.tb00918.x

Committee on Public Education. (2001). Children, adolescents, and television. *Pediatrics*, 107(2), 423-426. doi:10.1542/peds.107.2.423

Coyne, S.M., Padilla-Walker, L.M., & Stockdale, L. (2011). Game on Girls: Associations between co-playing video games and adolescent behavioral and family outcomes. *Journal of Adolescent Health*, 49(2):160-165. doi: 10.1016/j.jadohealth.2010.11.249.

Davis, N.O. & Carter, A.S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38, 1278-1291. doi:10.1007/s10803-007-0512-z

- de Bildt, A., Sytema, S., Ketelaars, C., Kraijer, D., Mulder, E., Volkmar, F., & Minderaa, R. (2004). Interrelationship between Autism Diagnostic Observation Schedule-Generic (ADOS-G), Autism Diagnostic Interview-Revised (ADI-R), and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) Classification in Children and Adolescents with Mental Retardation. *Journal of Autism and Developmental Disorders*, 34, 129–137. doi:10.1023/B:JADD.0000022604.22374.5f
- de Montigny, F. & Lacharite, C. (2005). Perceived parental efficacy: Concept analysis. *Journal of Advanced Nursing*, 49(4), 387-396.  
doi:10.1111/j.1365-2648.2004.03302.x#sthash.er6gA2NE.dpu
- Demarest, K. (2000) Video games –What are they good for? Retrieved from:  
<http://lesontutor.com/kd3.htm>
- Dempsey, I., Keen, D., Pennell, D., O'Reilly, J., & Neilands, J. (2009). Parent stress, parenting competence and family-centered support to young children with an intellectual or developmental disability. *Research in Developmental Disabilities*, 30, 558-566. doi:10.1016/j.ridd.2008.08.005
- Duarte, C. S., Bordin, I.A., Yazigi, L. & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*. 9(4), 416–427.  
doi: 10.1177/1362361305056081
- Eisenhower, A. and Blacher, J. (2006), Mothers of young adults with intellectual disability: Multiple roles, ethnicity and well-being. *Journal of Intellectual*

*Disability Research*, 50(12), 905–916. doi: 10.1111/j.1365-2788.2006.00913.x

- Ellingson, K.D., Briggs-Gowan, M.J., Carter, A.S. & Horwitz, S.M. (2004). Parent identification of early emerging child behavior problems: predictors of sharing parental concern with health providers. *Archives of Pediatric and Adolescent Medicine*, 158, 766–772. doi:10.1001/archpedi.158.8.766
- Ewoldsen, D.R., Eno, C.A., Okdie, B.M., Velez J.A., Guadagno, R.E., & DeCoster, J. (2012). Effect of playing violent video games cooperatively or competitively on subsequent cooperative behavior. *Cyberpsychology, Behavior, and Social Networking*, 15(5), 277-280. doi:10.1089/cyber.2011.0308.
- Farber, M.L.Z. & Maharaj, R. (2005). Empowering high-risk families of children with disabilities. *Research on Social Work Practice*, 15(6), 501-515. doi:10.1177/1049731505276412
- Fein, D., Barton, M., Eigsti, I.M., Kelley, E., Naigles, L., Schultz, R. T . . . Tyson, K. (2013), Optimal outcome in individuals with a history of autism. *Journal of Child Psychology and Psychiatry*, 54(2), 195–205. doi: 10.1111/jcpp.12037.
- Ferguson, B.R., Gillis, J.M., & Sevlever, M. (2013). A brief group intervention using video games to teach sportsmanship skills to children with autism

spectrum disorders. *Child & Family Behavior Therapy*, 35(4), 293-306.

doi:10.1080/07317107.2013.846648

Ferraioli, S. J., Hansford, A., & Harris, S. L. (2011). Benefits of including siblings in the treatment of autism spectrum disorders. *Cognitive and Behavioral Practice*, 1-10. doi: 10.1016/j.cbpra.2010.05.005

Flores, G., Abreu, M., Schwartz, I., & Hill, M. (2000). The importance of language and culture in pediatric care: Case studies from the Latino community. *The Journal of Pediatrics*, 137(6), 842-848. doi:10.1067/mpd.2000.109150

Flores, G., Olson, L., & Tomany-Korman, S.C. (2005). Racial and ethnic disparities in early childhood health and health care. *Pediatrics*, 115, 183-193. doi:10.1542/peds.2007-1243

Fombonne E. (2003). Epidemiologic trends in rates of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders* 33, 365-382.

doi:10.1017/CBO9780511544446.003

Freedman, B. & Naseef, R. (2012). A diagnosis of autism is not a prognosis of divorce: Myths and realities of maintaining a marriage as parents of a child with autism. *Autism Advocate*. Fall: 9-12.

doi:10.1177/136236131350952

Funk, J.B., Germann, J.N., & Buchman, D.D. (1997). Children and electronic games in the United States. *Trends in Communication*, 2, 111-126.

- Gallimore, R., Coots, J, Weisner, T., Garner, H., & Guthrie, D. (1996). Family responses to children with early developmental delays II: Accommodation intensity and activity in early and middle childhood, *American Journal on Mental Retardation*, *101*, 215-232.
- Garza, Y., Kinsworthy, S. & Watts, R.E. (2009). Child-parent relationship training as experienced by Hispanic parents: A phenomenological study. *International Journal of Play Therapy*, *18*(4), 217-228.  
doi:10.1037/a0017055
- Gentile, D.A., Anderson, C.A., Yukawa, S., Ihori, N., Saleem, M., Ming, L.K. . . Sakamoto, A. (2009). The effects of prosocial video games on prosocial behaviors: International evidence from correlational, longitudinal, and experimental studies. *Personality and Social Psychology Bulletin*, *35*, 752-763. Doi:10.1177/0146167209333304
- Gentile D.A., Lynch, P.J., Londer, J.R, & Walsh, D.A. (2004). The effects of violent video game habits on adolescent hostility, aggressive behaviors, and school performance. *Journal of Adolescent Psychology*, *1*, 5-22.  
doi:10.1016/j.adolescence.2003.10.002
- Gibaud-Wallston, J., & Wandersman, I.P. (1978, August). *Development and utility of Parental Sense of Competence*. Paper presented at the meeting of the American Psychological Association, Toronto, Canada.



- Gilmore L. & Cuskelly, M. (2008) Factor structure of the parenting sense of competence scale using a normative sample. *Child: Care, Health and Development*, 35(1), 48-55. doi:10.1111/j.1365-2214.2008.00867.x
- Gonzalez, M.C. (2011). *Family Interaction and Exercise Program: Treatment Manual*. (Unpublished manual). University of Illinois at Chicago, Chicago IL.
- Gottman, J.M. (1994). *What predicts divorce: The relationship between marital processes and marital outcomes*. Hillsdale NJ: Lawrence Erlbaum Associates.
- Granic, I., Lobel, A., & Engels, R.C.M.E. (2014). The benefits of playing games. *American Psychologist*, 69(1), 66-78. doi:10.1037/a0034857
- Gray, D.E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, 27(3), 215-222. Doi:10.1080/1366825021000008639
- Gray, D.E. (2003). Gender and coping: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976. doi:10.1111/j.1365-2788.2006.00933.x
- Greenberg J.S., Seltzer M.M., Krauss M.W., Chou R.J.A., & Hong J. (2004). The effect of quality of the relationship between mothers and adult children with schizophrenia, autism, or Down syndrome on maternal well-being:

- The mediating role of optimism. *American Journal of Orthopsychiatry* 74, 14–25. doi:10.1037/0002-9432.74.1.14
- Griffiths, M.D. (1997). Video games and clinical practice: Issues, uses, and treatments. *British Journal of Clinical Psychology*, 36(4), 639-641. doi:10.1111/j.2004-8260.1997.tb01271.x
- Griffiths, M.D. (1999). Video games and aggression: A review of the literature. *Aggression and Violent Behavior*, 4, 203-212. doi:10.1016/S1359-1789(97)00055-4
- Griffiths, M. D. (2002). The educational benefits of videogames. *Education and Health*, 20(3), 47-51. doi:10.1136/bmj.324.7346.1159
- Griffiths, M.D. (2003). The therapeutic use of videogames in childhood and adolescence. *Clinical Child Psychology Psychiatry*, 8, 547-555. doi:10.1177/13591045030084012
- Griffiths, M.D. (2005). The Therapeutic Value of Video Games, In K. Raessens, and J. Goldstein (Eds). *Handbook of Computer Games Studies*. (pp. 161-171). Cambridge, MA: The MIT Press.
- Gross, D., Garvey, C., Julion, W., Fogg, L., Tucker, S., & Mokros, H. (2009). Efficacy of the Chicago Parent Program with low-income African American and Latino parents of young children. *Society for Prevention Research*, 10, 54-65. doi:10.1007/s11121-008-0116-7

- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49, 405-418. doi:10.1111/j.1365-2788.2005.00673.x
- Hastings, R.P. & Brown, T. (2002). Behavioral problems of children with autism, parental self-efficacy, and mental health. *American Journal of Mental Retardation*, 107(3), 222- 232. Retrieved from <http://aspire-relationships.com/hastings6.pdf> on April 22, 2014.
- Hastings, R.P., Kovshoff, H., Brown, T., Ward., N.J., Degli Espinosa, F., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9(4), 377-391. doi:10.1177/1362361305056078
- Hastings, R.P. & Taunt, H.M. (2002) Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107, 222-232. doi:10.1352/0895-8017
- Hernandez, D.J. (2004). Demographic change and the life circumstances of immigrant families. *The Future of Children*, 14(2), 17-48. Retrieved from: [http://futureofchildren.org/futureofchildren/publications/docs/14\\_02\\_2.pdf](http://futureofchildren.org/futureofchildren/publications/docs/14_02_2.pdf) on May 14, 2014

- Higgins, D.J., Bailey, S.R., & Pearce, J.C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *The National Autistic Society*, 9(2), 125-137. doi:10.1177/1362361305051403
- Hobson, R.P., & Lee, A. (1998). Hello and goodbye: A study of social engagement in autism. *Journal of Autism and Developmental Disorders* 28(2), 117-127. doi:10.1023/A:1026088531558
- Horst, L., Werner, R., & Werner, C. (2000). Case management for children and families. *Journal of Child and Family Nursing*, 3, 5–14. doi:10.1007/978-90-481-9066-9\_13
- Iland, E.D. (2007). Half a Chance Is Not Enough: Latina Mothers of Children with Autism Struggle for Equity (Unpublished Masters' Thesis). California State University: Northridge, CA.
- Jerusalem, M. & Mittag, W. (1995). Self-efficacy in stressful life transitions. In A. Bandura (Ed.) *Self-efficacy in changing societies* (pp.177-201). New York, NY: Cambridge University Press.
- Johnston, C & Mash, E.J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology*, 18(2), 167-175. doi:10.1207/s15374424jccp1802\_8

- Jones, T., & Prinz, R. (2005). Potential roles of parental self-efficacy in parents and child adjustment: A review. *Clinical Psychology* 25(3), 341-363.  
doi:10.1016/j.cpr.2004.12.004
- Kaminski, J.W., Valle, L.A., Filene, J.H., & Boyle, C.L. (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of Abnormal Child Psychology*, 36, 567-589.  
doi:10.1007/s10802-007-9201-9
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-250.
- Kanner, L. (1949). Problems of nosology and psychodynamics in early childhood autism. *American Journal of Orthopsychiatry* 19(3), 416-426.  
doi:10.1111/j.1939-0025.1949.tb05441.x
- Katsikitis, M., Bignell, K., Rooskov, N., Elms, L., & Davidson, G.R. (2013). The family strengthening program: Influences on parental mood, parental sense of competence and family functioning. *Advances in Mental Health* 11(2), 143-151. doi:10.5172/jamh.2013.11.2.143
- Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders*, 4(2), 229-241. doi:10.1016/j.rasd.2009.09.009

- Kuhlthau, K., Orlich., F., Hall, T.A., Sikora, D., Kovacs, E., Delahaye, J., & Clemons, T.E. (2010). Health-related quality of life in children with autism spectrum disorders: Results from the Autism Treatment Network. *Journal of Autism and Developmental Disorders*, 40(6), 721-729. doi: 10.1007/s10803-009-0921-2
- Kuhn J. & Carter, A. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry* 76(4), 564-575. doi:10.1037/0002-9432.76.4.564
- Lambert, A.N. (2012). Evaluation of family impairment following an integrative treatment program for children with Autism (Unpublished doctoral dissertation). Adler School of Professional Psychology: Chicago, IL.
- Lantz, J. (2003). Assessment processes for autism spectrum disorders: Purpose and procedures. *The Reporter*, 8(1), 11-15. Retrieved from <http://www.iidc.indiana.edu/?pageId=365> on May 14, 2014.
- Lee, S.S., August, G.J., Bloomquist, M.L., Mathy, R., & Realmuto, G.M.(2006). Implementing an evidence-based preventative intervention in neighborhood family centers: Examining of perceived barriers to program participation. *The Journal of Primary Prevention*, 27(6) 573-597. doi:10.1007/s10935-006-0060-x

- Lenhart, A., Kahne, J., Middaugh, E., Macgill, E.R., Evans, C., & Vitak, J. (2008). *Teens, video games, and civics*. Washington, DC: Pew Internet; American Life Project.
- Lepper, M. R., & Henderlong, J. (2000). The little engine that had an incremental theory: An essay review of Dweck's "Self Theories." *Human Development, 74*, 186-190. doi:10.1159/000022675
- Levac, A., McCay, E., Merka, P., & Reddon-D'Arcy, M. (2008). Exploring parent participation in a parent training program for children's aggression: Understanding and illuminating mechanisms of change. *Journal of Child & Adolescent Psychiatric Nursing, 21*(2), 78-88. doi:10.1111/j.1744-6171.2008.00135.x
- Lieberman, D.A. (2006). What can we learn from playing interactive games? In P. Vorderer & J. Bryant (Eds.). *Playing video games: Motives, responses and consequences*. (pp. 379-398). Mahwah, NJ: Lawrence Erlbaum.
- Lindley, S., Le Couteur, J.L., & Bianchi-Berthouze, N. (2008). Stirring up experience through movement in game play: Effects on engagement and social behavior. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, April 5-10, 511-514. doi:10.1145/1357054.1357136
- Llewellyn, G., McConnell, D., Thompson, K. & Whybrow, S. (2005), Out-of-home placement of school-age children with disabilities and high support

needs. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 1–6.

doi:10.1111/j.1468-3148.2004.00201.x

Lopez, K. (2013). *Socio-cultural Perspectives of Latino Children with Autism and their Families* (Unpublished Doctoral dissertation). University of

Michigan: Ann Arbor, MI.

Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, A., ...

Rutter, M. (2000). Autism Diagnostic Observation Schedule: Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205-233.

Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2008). *Autism Diagnostic Observation Schedule Manual*. Los Angeles, CA: Western Psychological Services.

Lovejoy, M.C., Verda, M.R. & Hays, C.E. (1997). Convergent and discriminant validity of measures of parenting efficacy and control. *Journal of Clinical Child Psychology*, 26(4), 366-376. doi:10.1207/s15374424jccp2604\_5

Maciejewski, P.K., Prigerson, H.G., & Mazure, C.M. (2000). Self-efficacy as a mediator between stressful life events and depressive symptoms: Difference based on history of prior depression. *British Journal of Psychiatry*, 176, 373-378. doi:10.1192/bjp.176.4.373



- Mactavish, J., & Schleien, S. (2000). Exploring family recreation activities in families that include children with developmental disabilities. *Therapeutic Recreation Journal*, 34(2), 132-153.
- Magaña, S. & Ghosh, S. (2010). Latina mothers caring for a son or daughter with autism or schizophrenia: Similarities, differences, and the relationship between co-residency and maternal well-being. *Journal of Family Social Work*, 12(3), 227-250. doi:10.1080/10522150903514009
- Magaña, S. & Smith, M.J. (2006). Psychological distress and well-being of Latina and non-Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes towards co-residence status. *American Journal of Orthopsychiatry*, 76(3), 346-357. doi:10.1037/0002-9432.76.3.346
- Mandell, D.S., Wiggins, L.D., Carpenter, L.A., Daniels, J., DiGiuseppe, C., Durkin M.S. . . . Kirby, R.S. (2009). Racial/Ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493-498. doi:10.2105/AJPH.2007.131243
- Mannell, R.C. & Kleiber, D.A. (1997). *A Social Psychology of Leisure*. State College, PA: Venture.
- Marín, G., & Triandis, H. C. (1985). Allocentrism as an important characteristic of the behavior of Latin American and Hispanics. In R. Diaz (Ed.) *Cross-*

*cultural and national studies in social psychology* (pp. 85-104).

Amsterdam, Holland: Elsevier Science Publishers.

Markus, H. R. & Kitayama, S. (1991). Culture and the self: Implications for the cognition, emotion, and motivation. In R. F. Baumeister (Ed.). *The self in social psychology: Key readings in social psychology* (pp. 339-371). New York, NY: Psychology Press.

Mazurek, M.O. & Engelhardt, C.R. (2013). Video game use in boys with autism spectrum disorder, ADHD, or typical development. *Pediatrics*, *132*(2), 260-266. doi:10.1542/peds.2012-3956

Mian, N., Soto, T.W., Martinez-Pedraza, F., Maye, M., & Carter, A.S. (2012). *Clinical validation of the Family Life Impairment Scale in families raising a toddler on the autism spectrum*. Paper presented at the International Meeting for Autism Research, Toronto, Canada. Abstract retrieved from <https://imfar.confex.com/imfar/2012/webprogram/Paper11865.html>.

Minuchin, S. (1974). *Families & family therapy*. Cambridge, MA: Harvard University Press.

Moreno, C.L. (1995) *Understanding el autismo" A qualitative study of the parental interpretation of autism: A Hispanic Perspective*. Unpublished Doctoral Dissertation, Ohio State University: Columbus, OH.

Myers, B.J., Mackintosh, V.H., & Goin-Kochel, R.P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in

the autism spectrum has affected their lives and their families' lives.

*Research in Autism Spectrum Disorders* 3(3), 670-684.

doi:10.1016/j.rasd.2009.01.004

National Research Council (2001). *Educating children with autism*. Washington, DC: National Academy Press.

Ngui, E.M., & Flores, G. (2006.) Satisfaction with care and ease of using health care services among parents of children with special health care needs: The roles of race/ethnicity, insurance, language and adequacy of family-centered care. *Pediatrics*, 117(4), 1184-1196. doi:10.1542/peds.2005-1088

Nunnally, J. C. (1978). *Psychometric theory* (2nd ed.). New York, NY: McGraw-Unit.

O'Connor, T. G. (2002), Annotation: The 'effects' of parenting reconsidered: findings, challenges, and applications. *Journal of Child Psychology and Psychiatry*, 43(5), 555-572. doi:10.1111/1469-7610.00046

Ohan, J.L., Leung, D.W., & Johnston, C. (2000) The Parenting Sense of Competence Scale: Evidence of stable factor structure and validity. *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, 32(4), 251-261. Doi:10.1037/h008712

Olson, D.H., (1991). Three-dimensional (3-d) circumplex model and revised scoring of FACES-III. *Family Process*, 30, 74-79. doi:10.1111/j.1545-5300.1991.00074.x

- Osborne, L.A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(6), 1092–1103. doi:10.1007/s10803-007-0497-7
- Pearson, E. & Bailey, C. (2007). *Evaluating the potential of the Nintendo Wii to support disabled students in education. In ICT: Providing choices for learners and learning*. Poster session presented at the Australian Society for Computers in Learning in Tertiary Education, Singapore. Retrieved from <http://www.ascilite.org.au/conferences/singapore07/procs/pearson-poster.pdf>
- Peters-Scheffer, N., Didden, R., Korzilius, H. & Sturmey, P. (2012). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 60-69. doi:10.1016/j.rasd.2010.03.011
- Phelps, K.W., McCammon, S.L., Wuensch, K.L., & Golden, J.A. (2009). Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, 34(2), 133-141. doi:10.1080/13668250902845236

- Phetrasuwan, S. & Shandor Miles, M. (2009). Parenting Stress in Mothers of Children with Autism Spectrum Disorders. *Journal for Specialists in Pediatric Nursing, 14*(3), 157-165. doi:10.1111/j.1744-6155.2009.00188.x
- Piaget, J. (1951). *Play, dreams, and imitation in childhood*. London, England: Heinemann.
- Picard, R.W. & Goodwin, M.S. (2008). Developing innovative technology for future personalized autism research and treatment, *Autism Advocate, 50*(1), 32-39. Retrieved from <http://affect.media.mit.edu/pdfs/08.picard+goodwin-Advocate-final.pdf> on May 16, 2014.
- Randall, P., & Parker, J. (1999). *Supporting the families of children with autism*. New York, NY: Wiley.
- Rao, P.A. & Beidel, D.C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification, 33*(4), 437-451. doi: 10.1177/0145445509336427
- Review of the Vineland Adaptive Behavior Scales-Second Edition (2011). *Early Childhood Measurement and Evaluation Tool Review Edmonton, Alberta, Canada: Community-University Partnership for the Study of Children, Youth, and Families*. Retrieved from [http://www.cup.ualberta.ca/wp-content/uploads/2012/07/FINAL\\_Vineland\\_June-2012.pdf](http://www.cup.ualberta.ca/wp-content/uploads/2012/07/FINAL_Vineland_June-2012.pdf) on June 2, 2014.

- Rezendes, D. L., & Scarpa, A. (2011). Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: The roles of parenting stress and parenting self-efficacy. *Autism Research and Treatment, Vol 2011*, 1–10. doi:10.1155/2011/395190.
- Rice, C. (2007). Prevalence of autism spectrum disorders-autism and developmental disabilities monitoring network, 14 sites, United States, 2002. *Morbidity and Mortality Weekly Report, 56*, 12-28. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm> on May 12, 2014
- Rodrigue, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*, 371–379. doi:10.1207/s15374424jccp1904\_9
- Rogers-Dulan, J., & Blacher, J. (1995). African American families, religion, and disability: A conceptual framework, *Mental Retardation, 33*, 226-238.
- Rosas, R., Nussbaumb, M., Cumsillea, P., Marianovb, V., Correaa, M., Floresa, P. . . Salinas, M. (2003). Beyond Nintendo: Design and assessment of educational video games for first and second grade students. *Computers and Education 40*, 71-94. doi:10.1016/S0360-1315(02)00099-4
- Sabatelli, R.M. & Waldron, R.J. (1995). Measurement issues in the assessment of the experiences of parenthood. *Journal of Marriage and the Family, 57*, 969-980. doi:10.2307/353416

- Sanchez, L.L., (2006.) Barriers to diagnosis and treatment services faced by Latino parents of children with Autism: Understanding the needs of Latino families. (Unpublished Doctoral Dissertation) The Chicago School of Professional Psychology: Chicago, IL.
- Schertz, H. H. & Odom, S. L. (2007). Promoting joint attention in toddlers with autism: A parent-mediated developmental model. *Journal of Autism and Developmental Disorders*, 37, 1562-1575. doi:10.1007/s10803-006-0290-z
- Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children* (2nd ed.). New York, NY: Guilford Press.
- Sharpley, C.F., Bitsika, V. & Efremidis, B. (1997). Influences of gender, parental health, and perceived expertise of assistance upon stress, anxiety and depression among parents of children with autism. *Journal of Intellectual and Developmental Disorders* 38, 876-889.  
doi:10.1080/13668259700033261
- Shriver, M. D., & Allen, K. D. (2008). Beyond noncompliance: Developing evidence-based parent training interventions. In Shriver, M. and Allen, D. (Eds.) *Working with parents of noncompliant children: A guide to evidence-based parent training for practitioners and students* (pp. 159-186). Washington, DC: American Psychological Association.

- Shur-Fen Gau, S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., & Wu, Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6, 263-270. doi:10.1016/j.rasd.2011.05.007
- Sikora, D., Moran, E., Orlich, F., Hall, T.A., Kovacs, E.A., Delahaye, J. . . Kuhlthau, K. (2013). The relationship between family functioning and behavior problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(2), 307-315. doi:10.1016/j.rasd.2012.09.006
- Sisson, S.B., Broyles, S.T., Baker, B.L., & Katzmarzyk, P.T. (2010). Screen time, physical activity, and overweight in U.S. youth: National survey of children's health 2003. *Journal of Adolescent Health*, 47(3), 309-311. doi: 10.1016/j.jadohealth.2010.02.016.
- Sivberg, B. (2002). Family System and Coping Behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, 6(4), 397-409. doi:10.1177/1362361302006004006
- Skinner D, Bailey D, Correa V., & Rodriguez P. (1999). Narrating self and disability: Latino mothers' construction of meanings vis-á-vis their child with special needs. *Exceptional Child*, 65, 481-495. doi:10.1177/001440299906500404



- Smith, L., Hong, J., Seltzer, M., Greenberg, J., Almeida, D., & Bishop, S. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism & Developmental Disorders*, *40*(2), 167-178. doi:10.1007/s10803-009-0844-y
- Sparrow, S., Cicchetti, D., & Balla, D. (2005). *Vineland Adaptive Behavior Scales* (2nd ed.) Minneapolis, MN: Pearson Assessments.
- Stoner, J.B. & Angell, M.E. (2006). Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and Other Developmental Disabilities*, *21*(3), 177-189. doi:10.1177/10883576060210030601
- Teti, D.M. & Gelfand, D.M. (1991). Behavioral competence among mothers of infants in the first years: The mediational role of maternal self-efficacy. *Child Development*, *62*, 918-929. doi:10.1111/j.1467-8624.1991.tb01580.x
- Tomanik, S., Harris, G.E., Hawkins, J. (2004). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, *29*, 16-26. doi: 10.1080/13668250410001662892
- U.S. Census Bureau. (2012). *Statistical Abstract*. Retrieved from

<https://www.census.gov/prod/2011pubs/12statab/pop.pdf>

Vygotsky, L.S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Wakschlag, L.S. & Hans, S.L. (2000). Early parenthood in context: Implications for development and intervention. In: C.H. Zeanah (Ed.) *Handbook of infant mental health*. New York, NY: Guilford Press.

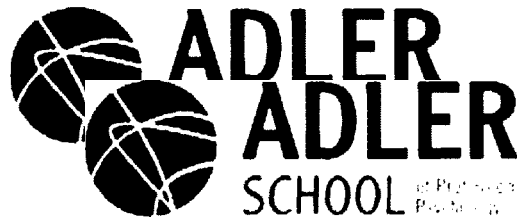
Wakschlag, L.S., Leventhal, B.L., Pine, D.S., Pickett, K.E. & Carter, A.S. (2006). Elucidating early mechanisms of developmental psychopathology: The case of prenatal smoking and disruptive behavior. *Child Development*, 77(4), 893–906. doi:10.1111/j.1467-8624.2006.00909.x

Weaver, C. M., Shaw, D. S., Dishion, T. J., & Wilson, M. N. (2008). Parenting self-efficacy and problem behavior in children at high risk for early conduct problems: The mediating role of maternal depression. *Infant Behavior and Development*, 31, 594–605.

doi:10.1016/j.infbeh.2008.07.006

Welterlin, A. & LaRue, R.H. (2007). Serving the needs of immigrant families of children with autism. *Disability & Society*, 22(7), 747-760.

doi:10.1080/09687590701659600



April 8, 2014

Dear Martha Citlaly Gonzalez,

The Institutional Review Board evaluated the changes to your protocol #14-062, *Evaluation of Family Functioning Following Parent Participation in Play Intervention for Children with Autism*. Your protocol has now received **Full Approval**. This decision means that you may proceed with your plan of research as it is proposed in your protocol.

Please note that if you wish to make changes to your protocol, you must provide written notification to the IRB in advance of the changes, co-signed by your Dissertation Chair, Dr. Cox. **You may not implement those changes until you have received a Full Approval letter from the IRB.** Please feel free to contact myself or other IRB committee members should you have any questions.

Sincerely,

A handwritten signature in black ink that reads "Peter Ji". The signature is written in a cursive, flowing style.

Peter Ji, Ph.D.  
Associate Professor  
Core Faculty, Psy.D. Program in Clinical Psychology  
Co-Chair, Institutional Review Board

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January 17, 2014

Adler School of Professional Psychology  
Institutional Review Board  
17 North Dearborn  
Chicago, IL 60602

To Whom It May Concern:

I am the principal investigator of the \_\_\_\_\_ In 2011, I agreed  
\_\_\_\_\_ use archival data for a pilot study of children with autism and their families who participated in  
a play group. Ms. Gonzalez proposed to examine the parental attitudes toward family functioning after  
participating in a play group with their children, including their child with autism. Data was collected  
under the oversight of the \_\_\_\_\_ Institutional Review Board (IRB) and  
within the project titled \_\_\_\_\_  
\_\_\_\_\_ of which I am \_\_\_\_\_ faculty sponsor

Citlaly agreed to protect the data in accordance with IRB policies and she has also agreed to adhere to  
the highest ethical standards in the protection of human subjects' information.

If you have any questions, you can reach me at \_\_\_\_\_ by email at \_\_\_\_\_

Sincerely yours,

Professor and Head

Table 1

*Descriptive Statistics*

	M	SD	Minimum	Maximum
Age of child with autism	7.09	1.51	5	9
Number of children in home	2.5	.82	2	4
Hours children spend playing video games (per week)	1.68	2.11	0	3.5
Hours spent engaging in family recreation (per week)	1.4	1.9	1	6

*M*=mean; *SD*=standard deviation

Table 2

*Means and Standard Deviations*

	Mean	SD	Normative Mean
PSOC (pre)	42.73	5.75	60.77
PSOC (post)	48.27	9.17	
Efficacy (pre)	15.64	3.01	
Efficacy (post)	20.36	5.68	
Satisfaction (pre)	23.00	4.34	
Satisfaction (post)	26.27	7.07	
FLIS (pre)	32.27	12.69	26.48
FLIS (post)	30.36	8.89	
Maladaptive Behavior Scale	19.72		

*\*The normative sample from Gilmore and Cuskelly's 2008 factor structure of the parenting sense of competence scale was used in the absence of an original normative sample. Only total scores were used as this had a 3-factor loading unlike Johnston and Mash's 2 factor loading.*

Table 3

*Paired T-test for Parental Competence and Family Impairment Pre-and Post-Intervention*

	Mean	SD	SEM	t	df	Sig.(2-tailed)
PostPSOC-PrePSOC	5.55	6.89	2.08	2.67	10	.024*
PostParentalCompetence	48.27	9.17	2.76			
PreParentalCompetence	42.72	5.75	1.73			
PostEfficacy-PreEfficacy	4.72	3.74	1.13	4.19	10	.002*
PostEfficacy	20.36	5.68	1.71			
PreEfficacy	15.64	3.01	.91			
PostSatis-PreSatis	3.27	4.5	1.36	2.40	10	.037*
PostSatisfaction	26.27	7.07	2.13			
PreSatisfaction	23.00	4.34	1.31			
PostFlis – PreFlis	-1.91	5.84	1.76	-1.08	10	.304
PostFlis	30.36	8.89	2.68			

PreFlis                                    32.27    12.69    3.83

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*\*p < .05*

Table 4  
*Pearson Correlation Analysis between Measures*

		MaladaptBx	FLISPost	PSOCPost
MaladaptBx	Pearson Correlation	1	.570	.512
	Sig. (2-tailed)		.067	.107
	N	11	11	11
TotalFlisPost	Pearson Correlation	.570	1	.601
	Sig. (2-tailed)	.067		.050*
	N	11	11	11
PostPSOC	Pearson Correlation	.512	.601	1
	Sig. (2-tailed)	.107	.050*	
	N	11	11	11

*\*p > .05*



Table 5

*Independent Sample Tests between one parent and two parent groups*

	Leverne's Test for Equality of Variances			t-test for Equality of Means			
	F	Si g.	t	df	P	SE	Descriptive
PSOCPPost	3.63	.09	-.96	9	.36	5.77	Not significant
FLISPost	.61	.46	-2.46	9	.04*	4.54	Significant

\* $p < .05$

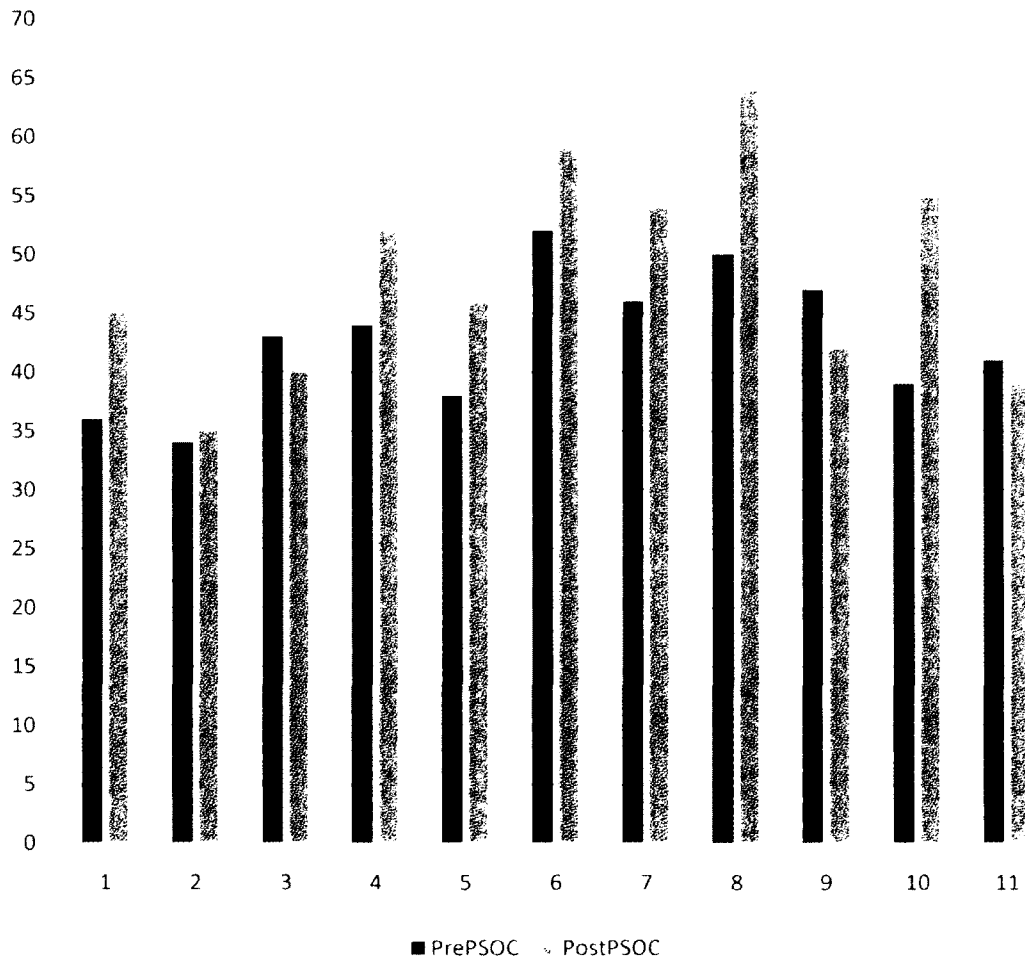


Figure 1. PSOC Descriptive Statistics: Scores for each participant at pre and post-testing demonstrate a trend of higher scores at post-testing.

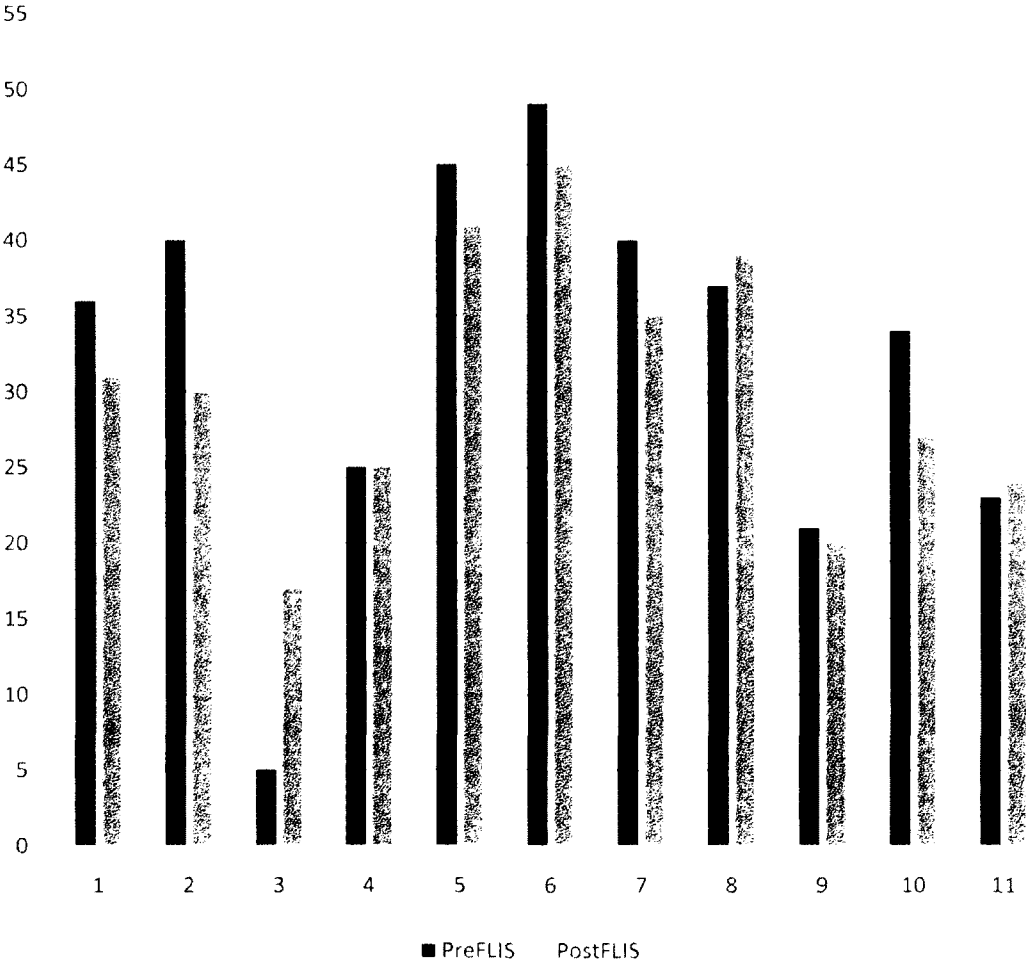


Figure 2. FLIS Descriptive Statistics: Scores for each participant at pre and post-testing demonstrate a trend of lower scores at post-testing.