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# The Role of Dispositional Optimism on Agency when Parenting a Child with Autism Spectrum Disorders

by Lina Maria Moyano

An Applied Dissertation Submitted to the Abraham S. Fischler School of Education in Partial Fulfillment of the Requirements for the Degree of Doctor of Education

## **Approval Page**

This applied dissertation was submitted by Lina Maria Moyano under the direction of the persons listed below. It was submitted to the Abraham S. Fischler School of Education and approved in partial fulfillment of the requirements for the degree of Doctor of Education at Nova Southeastern University.

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## Statement of Original Work ·

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My most humble gratitude and recognition goes to all the parents of children in the autism spectrum; to those who participated in the survey, thank you for taking your time to contribute to the advancement of research on positive topics in autism. To all the families who have crossed my path, from whom I have learned so much, I admire you and respect you. Thank you for allowing me to witness the love you have for your child. Within this group of parents, I especially recognize my friends Fabiola Torrez and Angelica Vidal for showing me the possibility of seeing autism as a blessing, and how having a child in the spectrum has enriched your life and that of those around you. Your love, acceptance and dedication have inspired me deeply.

Working with children with autism and their families has been a blessing to me.

To these families I dedicate this document and every day of my working life.

#### **Abstract**

The Role of Dispositional Optimism on Agency When Parenting A Child With Autism Spectrum Disorders. Lina Maria Moyano, 2013: Applied Dissertation, Nova Southeastern University, Abraham S. Fischler School of Education. ERIC Descriptors: Autism, Developmental Disorders, Parenting, Optimism, Parental Involvement, Agency

Parenting children with autism can be challenging obviously; still, active involvement of the parents is considered vital in the development of the child. The term parental agency refers to adopting a proactive role and engaging in numerous activities to promote the child's development. Little research has been conducted to analyze factors that could predict agency.

Dispositional optimism, which refers to expecting good things in life regardless of particular situations, has not been extensively studied in parents of children with autism. Nevertheless, the few studies conducted on the topic show it to be a desirable trait. Therefore, it is an important characteristic that needs to be studied in this population.

This applied dissertation was designed to examine a possible relationship between dispositional optimism and parental agency. Specifically, the main question explored was whether or not parents with higher level of dispositional optimism also reported higher agency. The writer administered via online the Life Orientation Test-Revised to measure dispositional optimism along with the Agency questionnaire to a group of parents (N = 126). A correlation between the two variables was not established. Other findings from the study suggest that maternal agency is significantly higher than that of males. Also, agency was not found to be related to age of the child, or parental education; however, there was a significant effect of non-white females on agency scores. Findings from this study point to the importance of implementing positive psychology strategies and promoting positive emotions among mothers of children with autism.

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#### **Chapter 1: Introduction**

Autism is a neurological disorder characterized by social deficits, communication impairment, and unusual ritualistic behavior (American Psychiatric Association [APA], 2000). According to the Centers for Disease Control and Prevention (CDC; 2012), 1 of every 88 children is diagnosed with autism, and although there are many different types of interventions, it is agreed that the role of the parents is crucial for the positive outcome of the child (Keen, Couzens, Muspratt, & Rodger, 2010; National Research Council, 2001; Sanefuji, Yamashita, & Ohgami, 2009; Schertz & Odom, 2007; Siller & Sigman, 2008). It is doubtful that any parent is prepared to rear a child with special needs and, although it is vital to adopt an active role in the development of their disabled child, many parents are not able to do so.

This active role is referred to as "agency." A parent who has high agency constantly learns about autism, maintains open communication with professionals, and decides on treatments to be followed, among other behaviors (Kuhn & Carter, 2006). Parents adopt agency in different levels, and factors that could influence agency need to be well studied.

Accepting the diagnosis of autism can be devastating for the parents, and therefore it could be hard to adopt an optimistic approach. Nevertheless, parents who enjoy the trait of "dispositional optimism," which refers to expecting good things in life regardless of specific circumstances, may adapt differently. Indeed, it is possible that dispositional optimism plays a role on agency (Scheier & Carver, 1985).

In the present study, the challenge of raising a child with Autism Spectrum

Disorders (ASDs), the need of parental agency, and the role of optimism was reviewed as

it led to a research study correlating dispositional optimism with active parental agency. In this chapter, an introduction to the problem studied and issues surrounding the topic are presented.

#### **Statement of the Problem**

The problem is that the effect of dispositional optimism on parental agency when raising children with autism is not known. Dispositional optimism could be an important trait affecting parental agency that has not yet been researched.

The rise in the prevalence of autism has become a national public concern (CDC, 2009). As this population grows and etiology of the condition is still not clear (CDC, 2009), the need to establish the provision of an effective intervention is evident. Research has shown the need and value of family center interventions (Keen et al., 2010; Reaven, 2011; Sanefuji et al., 2009; Schertz & Odom, 2007; Siller & Sigman, 2008). Still, adopting an active role can create burden for families, and therefore it is necessary to better understand factors that influence parental agency.

On the other hand, the benefits of dispositional optimism in diverse populations have been well documented; such benefits include adjusting better to stressful life events, and being proactive when facing problems (Carver, Scheier, & Segerstrom, 2010). If so, one could assume that parents who report higher levels of optimism are also more proactive in the development of their child with autism. A few studies have explored dispositional optimism among parents of children with autism (Baker, Blacher, & Olsson, 2005; Ekas, Lickenbrock, & Whitman, 2010; Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Warter, 2009); however, none considered dispositional optimism as a predictor of parental agency. There is a lack of research on dispositional optimism of parents of

children with autism as it relates to parental agency.

The topic. This study investigated the role of dispositional optimism in parental agency when raising a child with ASD. It is not clear if there is one specific characteristic that affects the level at which a parent becomes proactive when raising a child with autism. Dispositional optimism was evaluated as a predictor to agency.

The research problem. It has been well documented that parenting a child with a disability can be challenging and a source of tremendous levels of stress (Dabrowska & Pisula, 2010; Griffith, Hastings, Nash, & Hill, 2010; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). It is also well known that children benefit the most when their parents are involved in their development (National Research Council, 2001).

Considering the stress related to their parental role, it could be very difficult to become active participants in the child's development. It is important to investigate what specific characteristic, if any, would help the parent become highly involved. Dispositional optimism could be a significant trait that needs to be studied.

Background and justification. Challenges related to parenting a child with autism are obvious. Levels of stress are higher when compared to raising a typically developing child (Dabrowska & Pisula, 2010; Hoffman et al., 2009) as well as raising a child with another disability such as Down syndrome (Dabrowska & Pisula, 2010; Greenberg et al., 2004). Parental emotional well-being is clearly important. In fact, it has been shown that feelings associated with depression such as hopelessness, guilt, and difficulty concentrating can interfere with the ability to engage in the intervention (Kuhn & Carter, 2006), which again is vital for the positive development of the child. It is therefore essential to understand protective factors that could impact parental ability to

engage in the intervention.

Deficiencies in the evidence. There is extended literature regarding maternal well-being and coping mechanisms (e.g., Pisula & Kossakowska, 2010; Pottie & Ingram, 2008). It is also known that optimism is an important psychological characteristic that influences mental health (Carver et al., 2010); it plays an important role in well-being when parenting adults with autism and schizophrenia (Greenberg et al., 2004), as well as children with ASDs (Ekas et al., 2010). Considering that people with higher dispositional optimism take steps faster to deal with presenting problems than pessimistic people (Carver et al., 2010), it is imperative to investigate the role of this trait in relation to parental agency when raising a child with autism. This researcher did not find a study that specifically addresses this issue.

Audience. This study is beneficial to professionals in the field of autism as well as parents. This researcher, as a private practitioner, has coached parents to implement a relationship based intervention (DIR/Floortime model, which will be explained later in the paper) for the past decade. Working with families, one can witness some parents being more receptive and willing to actively engage than others, which may be frustrating for the professional. Nevertheless, when encouraging parents to become more active, it is important for professionals to be aware and respect personality characteristics of the parents that would influence their involvement. If optimism is in fact an important factor to agency, ways to promote this trait need to be explored. Helping parents reframing problems faced in regards to the child significantly improves their involvement and therefore the development of the child (Durand, Hieneman, Clarke, Wang, & Rinaldi, 2012). In addition, information obtained will also benefit parents directly affected, who

could become cognizant of their own optimistic/pessimistic traits and their level of involvement. This new information will be added to the general fund of knowledge and available to the public by submitting the final manuscript to ProQuest Dissertation and Theses database.

#### **Definition of Terms**

Agency. "Agency is the extent to which a mother (or father) assumes an active role in her child's development, engages in interactions with her child, and persists in identifying strategies that minimize maladaptive child behaviors and maximize adaptive behaviors" (Kuhn & Carter, 2006, p. 565). This definition will be adopted for the purpose of this research. The concept of agency thinking has also been described as a motivational component of hope that "reflects the belief that one can initiate *and* sustain movement along the imagined pathways to goals" (Snyder, 2000, p. 13).

Dispositional Optimism. Dispositional optimism is defined as a general expectation of positive outcomes in life (Scheier & Carver, 1985). It is considered a complete set of confidence pertaining to life in general rather than a specific situation. An optimist would act confidently and persistently in the face of challenges (Carver et al., 2010). It has been argued that pessimists are a minority and that most people are optimists in varying degrees. It is considered a desirable trait that has been related to positive well-being during challenging times, positive coping techniques, better physical health, persistence in education, and higher income (Carver et al., 2010).

#### **Purpose of the Study**

The purpose of this study was to investigate dispositional optimism as a factor related to the extent a parent assumes an active role in the child's development when

raising a child with autism. There are many factors associated with how successful a parent is at dealing with the diagnosis of the child. Number of children in the house, support system, severity of diagnosis, parental locus of control, coping styles, and well-being are just a few contributing factors to parental adjustment (Konstantareas, 1991; Olivier & Hing, 2009). This research, however, specifically looked into dispositional optimism to determine its role in agency as it had not been studied before.

#### **Chapter 2: Literature Review**

To understand the rationale of this investigation, literature surrounding various topics needed reviewing. For that purpose, this chapter begins by briefly exploring autism disorders; then a review the numerous challenges that come with raising a child with autism and the literature pertaining to the importance and benefits of parental involvement follows. Continuing, the concept of agency, closely related to parental involvement is explored as well as investigations that have considered the topic.

Optimism is introduced and reviewed as it relates to parents of children with autism.

Furthermore, the theoretical framework used in this study and the research questions investigated are presented.

#### **History and Prevalence of Autism**

The term autism was first used by Leo Kanner, to describe childhood schizophrenia traits (Folstein, 1999). In 1943, Kanner reported 11 cases of children with social deficits, ritualistic behavior, and word repetition; the following year, Hans Asperger described children with the same characteristics portrayed by Kanner (Sanders, 2009). It was not until 1980, however, that autism was included in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) under the category of psychiatric disorders (Sanders, 2009).

In 1994, the fourth edition of the DSM added a category of Pervasive

Developmental Disorders (PDD), which included the following subtypes: autism

disorder, Asperger's disorder, Rett's disorder, childhood disintegrative disorder (CDD),
and pervasive developmental disorder not otherwise specified (PDD-NOS; Sanders,
2009). Currently, autism, Asperger's, and PDD-NOS are commonly referred to as ASDs

(Autism Spectrum Disorders).

Some of the diagnostic changes in the DSM-IV included the addition of the PDD-NOS subcategory that refers to individuals presenting characteristics of autism, but failing to satisfy the full criteria of the condition. It has been claimed that such a subcategory provides clinicians with unclear diagnostic guidelines (Buitelaar, Van der Gaag, Klin, & Volkmar, 1999). Similarly, the addition of Asperger's disorder has been criticized since it might refer to a quantitative manifestation of the same disorder (Sanders, 2009). In the DSM-V released in May of 2013, however, diagnosis criteria have been changed with the removal of Rett's Disorder and CDD, Asperger's, and PDD-NOS subsumed under the existing Autism Disorder diagnosis (APA, 2013).

Initially, autism was considered a rare disorder; nonetheless, in the late '90s reports of incidence increase started to emerge (Folstein, 1999). Hence, the CDC took serious steps to learn more about the disorder and to track the incidence of autism in the United States. The Autism & Developmental Disabilities Monitoring (ADDM) Network was established and funded by the CDC in 2000 in an effort to establish prevalence of autism over time and to acquire a better understanding of autism (CDC, 2007).

The latest autism prevalence study conducted by the CDC reports that the average number of 8-year-old children with autism was 11.3 per 1,000 children with male occurrences being 4.6 higher than female (CDC, 2012). Some researchers suggest that such increases could be attributed to methodological procedures, expansion of diagnostic criteria, and more awareness of the disorder (Wazana, Bresnahan, & Kline, 2007). Indeed, some assure that changes in diagnostic criteria from DSM-III to DSM-IV might account for 1.4-fold increases in frequency of autism (Wazana et al., 2007); interestingly,

others have reported that growing prevalence of autism was associated with decreased diagnosis of other disorders such as mental retardation and learning disabilities (Shattuck, 2006). Although historically, early accounts of autism are not clear (Wolff, 2004), a true incidence rise of autism is not ruled out (CDC, 2009; Wazana et al., 2007).

In any case, it is clear that our society faces a challenge now. Parents struggle to obtain accurate diagnoses, while medical doctors do not diagnose signs of autism (Stoner et al., 2005). Professionals across different fields need to be better educated about ASDs, prepared to provide services and guide parents through the puzzle of autism.

#### **Characteristics of Autism**

Nearly 70 years have passed since autism was first identified; nonetheless, the condition still remains a mystery, its etiology unknown (CDC, 2009; Johnson & Myers, 2007; Strathearn, 2009), and a cure for the condition yet to be established (National Autism Center, 2009). In this segment, a brief review of the characteristics of the disorder will be provided.

Autism is said to be a neurological disorder with strong genetic influence and some environmental influence as well (Johnson & Myers, 2007). It is usually diagnosed during childhood, and it manifests with broad features heterogeneity among individuals, which makes its recognition challenging. In general terms, nonetheless, absence of shared attention, referring to the ability to follow someone's gaze and jointly attend an external object, is one of the earliest distinct markers of autism in toddlers (Schertz & Odom, 2007). Other early signs of autism include limited eye contact, little or no response to name or sounds, delayed speech development, extremes of temperament and behavior, and preference for solitary play (Johnson & Myers, 2007).

Contrary to common belief, cognitive skills vary greatly among individual with autism going from extremely low IQ to superior abilities; some show limited interest in specific topics and lack of abstract thinking (Grossberg & Seidman, 2006). In addition, it is claimed that most individuals in the spectrum fail to recognize the emotions of others, which is termed theory of mind (Baron-Cohen, Leslie, & Frith, 1985). Many others have sensory processing deficiencies, which means they might overreact, or under react to different sensory modalities, or fail to integrate such modalities (Fazlioglu & Baran, 2008). It is claimed that behaviors such as stereotypic motor movements, aggression, aimless running, and self-injurious behaviors are linked to sensory integration deficits (Pfeiffer, Koenig, Kinnealey, & Henderson, 2011).

Considering the characteristics of autism mentioned above, it is fair to consider that parents must be full of patience and perseverance to successfully face the challenges that come with the condition. It is also important that professionals become cognizant and sensitive to those challenges in order to communicate with parents in an empathetic way that would strengthen the therapeutic relationship.

#### **Treatment Options**

Although there are numerous treatment options to autism (National Autism Center, 2009), the most recognized interventions will be briefly reviewed in this section.

Applied Behavior Analysis (ABA). This model encompasses a variety of methods based on operant conditioning. Although its application is not exclusive to individuals with autism, it is very popular among this population. In general terms, the main premise of this intervention is that deficits related to autism are defined as behaviors that can be taught through the use of reinforcers. Therapeutic methods within this

approach include Discrete Trial Training (DTT), Picture Exchange Communication System (PECS), Verbal Behavior Analysis (VBA), Functional Communication Training (FCT), Pivotal Response Training (PRT), and incidental teaching among others (Dillenburger & Keenan, 2009).

DIR/Floortime model. The Developmental, Individual Differences,
Relationship-based approach (DIR)/Floortime model targets core functional emotional
capacities children in the spectrum lack, which are attention and co-regulation,
engagement, two-way communication, and the ability to problem solve in a social
context. This is done by playful "floortime" interaction in which the adult follows the
lead of the child, emphasizing affect and gestures, and then challenges the child in a
purposeful manner. This is a family based approach in which the relationship with the
child is highlighted, as well as his/her individuality. In this intervention, parents are
coached to implement floortime in the natural setting (Wieder & Greenspan, 2003).

Speech and language therapy. As discussed above, communication is one of the core deficits in autism. This type of intervention specifically targets this deficiency; a certified speech and language pathologist would work with the child individually or in a group setting, and would incorporate activities to promote proper verbal and non-verbal communication (Johnson & Myers, 2007). According to the American Speech-Language-Hearing Association (2006), professionals in that field would enhance the initiation of spontaneous language, comprehension of communication across settings, communication for social functions, and verbal and non-verbal expression, which can incorporate the use of augmentative and alternative communication systems.

Occupational therapy. Occupational therapists are usually part of the interdisciplinary plan in assessment and treatment of autism. Most children in the spectrum are recommended this therapy to target skills related to daily functioning. For this intervention a certified occupational therapist would evaluate the child and set specific goals related to fine motor skills, gross motor skills, sensory-processing, motor planning, posture and balance, visual-spatial processing, and body awareness.

Therapeutic activities consider the environmental context, the individuality of the child and the demands of the activity; they are usually child-led (American Occupational Therapy Association, 2010).

Dietary and biomedical interventions. The basic premise of this intervention is that there are biological components that affect the functioning of the child in a unique way and such components need to be addressed for the child to learn better; in other words, dietary, nutritional, and medical therapy improve efficacy of other interventions, such as those discussed above. This treatment may include food sensitivity tests, gluten and casein free diet, vitamin and mineral supplements, gut treatments, thyroid supplements, sulfation, chelation, immune system regulation, and hyperbaric oxygen therapy (Adams, 2013).

#### **Challenges in Parenting a Child with Autism**

Without a doubt, venturing on the road of raising a child is no easy task for any new parent. Accommodating to a new schedule, adjusting finances, and sacrificing leisure time are only a few initial challenges that every parent has to go through. When adding a child with a disability to the equation, parents will face much greater difficulties. First of all, many parents struggle to get a diagnosis (Stoner et al., 2005); once the

diagnosis is given, they enter the grieving process, which can be painful and lengthy. Selecting therapies and paying for them, advocating for services, caring for siblings, while struggling to maintain a marital relationship are only some of the challenges parents face.

Getting the diagnosis. Stoner et al. (2005) have reported that many parents struggle even before getting a diagnosis; parents that participated in their interviews explained that professionals continued dismissing their concerns with a "wait and see" attitude. Most parents (85%) report concerns before professionals had seen signs of alarm (Guinchat et al., 2012). On the other hand, other parents struggle to accept that there could be something wrong in the child's development and remain in denial for some time (Olivier & Hing, 2009). In either case, sadly, only a minority of primary care pediatricians use formal developmental screening tools and a few specifically screen for ASD (Johnson & Myers, 2007). It has been reported that the delay between first parental concerns and acquiring a formal diagnosis has a dramatic effect on parental stress (Osborne & Reed, 2008). Not surprisingly, higher parental stress during the diagnosis process is associated with a higher number of professionals consulted and lower perceived collaboration (Moh & Magiati, 2012).

Finally when a diagnosis is given, many parents report feeling relieved: "Our suspicions as being those that actually live and bring up our child were actually founded, that we weren't sort of quite mad or paranoid" (Osborne & Reed, 2008, p. 315). In any case, considering that early intervention is crucial, parents need to be proactive to have their child properly evaluated as soon as a sign of atypical development is observed.

**Grieving and coping.** Once a diagnosis is received, things do not get better, and

still parents must find ways to cope and face the new challenges. It is intriguing to point out, however, that parents vary significantly in their ability to do so with some experiencing severe mental health problems, while others face few of those issues (Benson, 2010). It is even more interesting that many parents even gain in personal growth, relationships with others, patience and empathy, as a result of raising a child with autism (Hastings & Taunt, 2002). For instance, when asked "How has your child in the autism spectrum affected your life and your family's life?" someone replied: "ruined it," while someone else answered: "he is a blessing! A gift from God! Helps everyone in our home spiritually!" (Myers, Mackintosh, & Goin-Kochel, 2009, p. 673). Unfortunately, most parents answer with a negative or mixed tone with some even reporting suicidal thoughts after learning about the diagnosis (Myers et al., 2009).

Regarding coping modalities, it is not surprising that mothers who cope through distraction and disengagement (substance use, denial, and giving up attempts to cope) report higher depressed moods, as opposed to those who cope via engagement (approach oriented), and cognitive reframing (Benson, 2010). Similar findings correlate problem focusing, social support, positive reframing, emotional regulation, and compromise coping mechanisms to positive mood (Pottie & Ingram, 2008). Moreover, positive coping skills such as seeking support and attempting to self-regulate are associated with a higher sense of coherence, which refers to a feeling of perseverance to overcome obstacles; on the other hand, rationally accepting responsibility without engaging in action relates to lower sense of coherence (Pisula & Kossakowska, 2010). It is important for professionals to consider coping mechanisms used by parents and encourage those that would lead to more positive outcomes.

**Specifics of the diagnosis.** Different studies have pointed out that due to the specific characteristics of the diagnosis, raising a child with autism is more challenging in comparison to raising typically developing children (Gau et al., 2012; Hoffman et al., 2009) and children with other disabilities such as Down syndrome (Dabrowska, & Pisula, 2010; Greenberg et al., 2004; Griffith et al., 2010).

Indeed, when compared to mothers of children with Down syndrome, those raising children with autism experience higher stress, have lower positive perception of their kids (Griffith et al., 2010), report higher levels of depression (Greenberg et al., 2004), higher levels of worry, and lower levels of hope (Ogston, Mackintosh, & Myers, 2011). It is not difficult to imagine that a parent of a child with ASD could be easily frustrated as the child refuses to interact, or becomes aggressive or self-absorbed; stereotypical behavior can be stressful for parents, especially in a public setting. Often times, parents take those behaviors personal and report feelings of failure at parenting (Myers et al., 2009).

Furthermore, considering that autism does not come with physical identifiable traits, people do not recognize it in public settings. Instead, they see a child acting out and many people are quick to assume that the misbehavior must be the result of bad parenting (Neely-Barnes, Hall, Roberts, & Graff, 2011). The same is true about extended family; many grandparents remain in denial, and believe misbehavior must be corrected by the parents (Neely-Barnes et al., 2011).

Severity of the condition is also a factor that must be considered. It has been reported that it influences maternal depression (Benson, 2010), and it negatively correlates with parental involvement (Benson, Karlof, & Siperstein, 2008), and family

burden (Stuart & McGrew, 2009). According to Benson et al. (2008), when a child's condition is so severe, the parent only has the energy to watch him or her and keep him or her safe. It is claimed that parents of children with severe autism worry more and report lower hope (Ogston et al., 2011). Others, on the other hand, have not found a similar correlation between severity of the child's condition and maternal stress (Peters-Scheffer, Didden, & Korzilius, 2012) or maternal mood (Pottie & Ingram, 2008).

Selecting therapies. As attention to the condition and its prevalence has increased, treatment options have also skyrocketed (National Autism Center, 2009). For instance, Behavior Therapy, DIR/Floortime, Speech Therapy, Occupational Therapy, Functional Communication Training (FCT), Relationship Development Intervention (RDI), Pivotal Response Training (PRT), chelation, hyperbaric oxygen therapy, auditory integration training, music therapy, and gluten and casein free diets are only a few examples of current treatment approaches to autism.

When it comes to deciding on which of the numerous existing types of therapies to treat ASD to choose, parents find contradicting information regarding efficacy of interventions (Goin-Kochel, Mackintosh, & Myers, 2009). As reported by Osborne and Reed (2008), many parents report not receiving enough information about the condition and services available to their child; and therefore the burden of deciding which therapy to use can be a struggle. Nowadays, it is safe to affirm that the Internet is the most accessed source of information, and a Google search of the words "autism treatment" leads to about 79,900,000 results, leaving a new parent with an overwhelming amount of contradicting information. Websites of national autism associations are likely to be appealing to parents searching treatment options; nevertheless, after evaluating the

quality of information posted in such websites, Stephenson, Carter, and Kemp (2012) concluded that limited guidance for parents and teachers is provided regarding the selection of evidence-based interventions.

With so many choices available, unsurprisingly, it has been reported that many parents select interventions that lack scientific support (Regehr & Feldman, 2009), while many incorporate a variety of alternative approaches, some of which are possibly helpful and others even harmful (Goin-Kochel et al., 2009). Indeed, many families may be drawn to select non-scientific interventions as a desperate hope to help the child (Regehr & Feldman, 2009).

Finances. Once a decision has been made regarding route of action, the parents of a child with autism have to meet financial obligations in an effort to provide the best available services for the child. Interventions are usually expensive and require several hours per week. Unfortunately, direct services cost is not the only source of financial struggle; for instance, parents have reported that their careers and incomes have been negatively affected by the child's disorder (Jarbrink, Fombonne, & Knapp, 2003). Informal care and additional monetary outlays constitute a financial burden for families of children with autism (Jarbrink et al., 2003). Moreover, costs related to medical services add to the struggle; indeed, children with autism have substantial burden of medical illnesses where an estimated annual cost related to medical visits is \$6,132 as opposed to \$860 for children without autism (Liptak, Stuart, & Auinger, 2006).

It is not surprising that financial struggle is more likely to occur among families with lower income than among families making over \$60,000 per year (Sharpe & Baker, 2007); it also has been reported that obtaining therapy for the child with autism is

consistently a priority over all other family needs, forcing many to cash in their 401k plans early, take out a home equity loan, max out credit cards, and even file bankruptcy (Sharpe & Baker, 2007).

**Advocating.** In addition to struggling financially, many families also suffer advocating for services. Anger and frustration is common regarding schools, insurance coverage, and lack of community services (Myers et al., 2009). Parents, hence, must also find the strength to confront school personnel and insurance companies to get adequate services needed for the child.

It is common that parents complain about their experiences with school and with the Individualized Education Program (IEP) meeting. According to parents, school personnel do not recognize the individuality of the child, and focus on the disabilities rather than the strengths of each child (Shelden, Angell, Stoner, & Roseland, 2010). In a study by Stoner et al. (2005), after interviewing parents regarding the initial IEP meeting, all participants perceived it as traumatic, confusing and complicated, which led to dissatisfaction towards the special education system. As a parent narrates: "If you have never been to an IEP meeting, you have no idea how intimidating that they can be, even for a very confident person, everyone should have an advocate to go with them." (Roth, 2012, para. 18).

Marital satisfaction and divorce rates. Clearly, relationships within couples are challenged when stressful situations are being faced. Hence, it has been documented that parents of children with autism report lower martial happiness, marital adjustment difficulties, and less sense of consensus than parents of children developing typically (Gau et al., 2012). In addition, mothers perceive less dyadic satisfaction and affective

expression than their male counterparts. They also report more marital maladjustments than their husbands (Gau et al., 2012). Couples suffer from lack of privacy, with little to no opportunities of going on dates sometimes because of the demands of the child and others because of husbands who avoid coming home (Myers et al., 2009). Arguments about the child's condition add to the strains. All these factors could possibly lead to divorce; "husband took off due to stress" explained a mother (Myers et al., 2009, p. 677).

Mixed experiences surround this topic; for instance, while 75 respondents reported marital constrains, 8 reported their marriage was enriched due to the child's condition (Myers et al., 2009). Moreover, a review of literature claims contradictory evidence regarding divorce rates and marital satisfaction and that the negative impact of raising a child with autism on the marital relations could actually be lower than once thought (Meadan, Halle, & Ebata, 2010). For instance, Hartley et al. (2010) reported that parents of children with ASD have higher rates of divorce than the control group (23.5% vs. 13.8%). On the other hand, other researchers found that 64% of children with autism lived with married or adoptive parents, and an almost equal percentage of children without ASD had the same living arrangements (Freedman, Kalb, Zablotsky, & Stuart, 2012), which discredits the divorce in autism controversy. According to their epidemiological study, there is no evidence to suggest that children with ASD are at an increased risk of living without both parents (Freedman et al., 2012).

**Siblings.** Due to the considerable amount of stress that parents of children with autism bear, it is not surprising that siblings are also affected. Some of them do not understand the condition and some others might feel embarrassed about their brother's or sister's behavior (Myers et al., 2009); still, other groups may become more sensitive and

compassionate as a result of having a sibling with autism (Myers et al., 2009). According to Meadan et al. (2010), mixed findings have been drawn regarding positive and negative experiences of siblings of ASD children. Some have reported that such populations are at risk of behavioral and emotional difficulties (Petalas et al., 2012); while others do not report the same negative outcomes (Benson & Karlof, 2008), or any difference in maladjustments between siblings of ASD children and siblings of typical children (Quintero & McIntyre, 2010; Tomeny, Barry, & Bader, 2012).

It has been argued that such contradictory findings on sibling adjustment might relate to the role of Broad Autism Phenotype (BAP; Meyer, Ingersoll, & Hambrick, 2011; Petalas et al., 2012). BAP refers to a set of personality traits, social, cognitive and language deficits often found among family members of individuals in the autism spectrum (Meyer et al., 2011). Indeed, the presence of BAP among siblings has been directly linked to sibling adjustment (Meyer et al., 2011). Similarly, Petalas et al. (2012) found that sibling adjustment was related to the behavioral problems of the ASD child and to the sibling BAP features. Considering the BAP phenomenon, many families struggle deciding whether or not to have more children, and risk raising more than one child with an ASD diagnosis (Regehr & Feldman, 2009).

As for mothers, a feeling of guilt for not giving enough time and attention to the typically developing child appears common (Meirsschaut, Roeyers, & Warreyn, 2010). It is not surprising that a mother will give extra attention to the one with special needs, which could make the typical child feel less important. Nevertheless, a parent being proactive to ameliorate the child's condition does not influence sibling adjustment; indeed the opposite is true. In other words, there is a clear relationship between increased

parental educational involvement and positive sibling adjustment (Benson & Karlof, 2008). This could be explained considering that when parental knowledge of autism is high, depression would be lower (Bristol, Gallagher, & Holt, 1993), and in turn the parents would be able to create a positive atmosphere within the family, which would affect all the members of the unit.

On the opposite side, it is interesting to note that maternal depressive symptoms predict sibling adjustment problems (Meyer et al., 2011; Quintero & McIntyre, 2010), which again points to the importance of maternal well-being and the significance of considering the experience of every individual within the family system.

#### **Benefits of Parental Involvement**

According to the National Research Council (2001), parental involvement represents a crucial "best practice" in educating children with ASDs. The importance of parental involvement is broadly recognized, and it has even been vitally included in the legal mandate. In the Individuals with Disabilities Education Act (IDEA), it is highlighted that parents must be full and equal participants with the district in the development of the Individual Educational Program (IEP) of each student, which some have considered the most basic of all legal requirements related to the IEP (Christle & Yell, 2010).

It is interesting to note that regardless of the treatment modality followed, advocacy for parental involvement is a common denominator across treatment options. For instance, in the DIR/Floortime model, the Functional Communication Training, and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), among others, positive outcomes are related to parental involvement

(Bennett, 2012). Besides, it has been noted that programs that include parental education have a positive impact on the children and their parents as well (Meadan et al., 2010). Such benefits will be discussed in this section.

Benefits of involvement for the child. Much has been said about the benefits of parent mediated interventions (National Research Council, 2001; Sanefuji et al., 2009; Schertz & Odom, 2007; Siller & Sigman, 2008). Some have even argued that parents are the major influence on their child's development even when the child receives diverse therapies (Mahoney, 2009). It is not surprising that as a parent becomes involved and acquires improved skills, ongoing opportunities for learning and development in the natural environment will occur, which would lead to positive outcomes for the child (McConachie & Diggle, 2007).

For instance, in a randomized controlled trial, children whose parents were trained in a home-based floortime program showed increase in functional emotional development as well as decrease in autistic symptoms (Pajareya & Nopmaneejumruslers, 2011). Similar findings were reported in a pilot study based on the same model: 45.5 % of children who participated in the study made "good" to "very good" functional developmental progress over the 2-year study period. Interestingly, positive outcomes were correlated to the amount of hours parents engaged in therapeutic play (Solomon, Necheles, Ferch, & Bruckman, 2007).

Moreover, others suggest that early abilities such as joint attention, a basic non-verbal communication milestone that children with autism lack, emerge as a result of mother's imitating the infant (Sanefuji et al., 2009). The mother in this single-subject design reported that the quality of her interaction with her 21-month-old daughter

diagnosed with autism improved because of the intervention (Sanefuji et al., 2009). Correspondingly, others have also established the emergence of joint attention among toddlers as a result of a parent mediated-relationship based model in which parents were instructed to engage in face-to-face interaction with their offspring for at least one hour per day (Schertz & Odom, 2007); language increases were observed by the clinicians and the parents after the intervention. Others have reported similar results: increases in communication have been observed by parents who followed a family-based intervention (Keen et al., 2010).

Results by Keen et al. (2010) are not surprising considering that join attention is considered a precursor of language abilities (Siller & Sigman, 2008). The importance of parental involvement and its impact in language acquisition was also highlighted in a longitudinal study that followed 28 children during early and middle childhood (Siller & Sigma, 2008). Data obtained through assessment scales and video-tape analysis revealed that children had higher language development when parents were responsive during play and when the child was responsive to bids for joint attention (Siller & Sigman, 2008).

In older populations, the role of parents still proves important. As the child grows older, the presence of anxiety can be especially debilitating among adolescents with high functioning autism (Reaven, 2011). At that point, research recommends that parents be educated about this co-morbid condition, and trained in relaxation techniques, cognitive restructuring exercises, graded exposure and relapse prevention, as well as modeling their own brave behavior (Reaven, 2011). In a similar manner, others assure that the emergence of self-determination in adolescents, which has been defined as the ability to engage in goal-directed activities, is related to the role of parents (Field & Hoffman,

1999). Indeed, this important skill can be promoted by parents first acting as role models and also creating opportunities and providing support in activities that aim for self-determination (Field & Hoffman, 1999). In essence, it can be stated that as a parent is involved in the development of the child, the child will show enhanced development.

Benefits of involvement for the parents. Most of the studies mentioned above reported that as parents learned how to better reach out to their child, they felt more confident at the interaction and therefore more open to free play with their child, which resulted in better developmental outcome for the child (Mahoney, 2009; Sanefuji et al., 2009; Schertz & Odom, 2007; Siller & Sigman, 2008). Others have concluded that parent education and family focused early intervention programs reduce levels of depression (Bristol et al., 1993) and parental stress and increase their sense of competence (Keen et al., 2010; Schultz, Schmidt, & Stichter, 2011). Many parents feel empowered and in control of their home (Dillenburger, Keenan, Gallagher, McElhinney, 2004).

Some interventions such as "Relationship Focused Intervention" (RFI) encourage parents to be responsive and actively engage with the child. According to Mahoney (2009), RFI attempts to boost the quality or effectiveness of parents with their children during daily activities and routines, which in turn increases parental responsiveness.

In summary, a meta-analysis suggests that parent training can lead to several benefits such as improved child communicative behavior, increased parental knowledge of autism, enhanced parental communication style and parent child interaction, and reduced parental depression; however, more investigation with adequate randomized control research designs is called for (McConachie & Diggle, 2007).

#### **Agency**

Parent education (or parent training) broadly refers to programs or trainings designed to provide parents with information or teach them skills (Schultz et al., 2011). The concept of agency is related to parental involvement; nevertheless, it goes a step further than merely participating in education. Kuhn and Carter (2006) defined it as "the extent to which a mother (parent) assumes an active role in her child's development, engages in interactions with her child, and persists in identifying strategies that minimize maladaptive child's behaviors and maximize adaptive behaviors" (p. 565). In fact, many parents may participate in a training program or be present in the room while the child receives therapy; still, their efforts may go no further than that. A high-agency-parent, on the other hand, also learns about autism, keeps an open communication with school personnel/therapists, advocates for the child and actively decides on what therapies to follow, for instance. Also, parental involvement can be hard to measure; agency, on the other hand, has been conceptualized and a validated tool has been created to assess it (Kuhn & Carter, 2006).

According to Kuhn and Carter (2006), mothers who report high agency also report high levels of self-efficacy, which means they feel confident in their caretaker role. This is not surprising as the same has been reported regarding parent-focused interventions (Keen et al., 2010). Interestingly, results from Kuhn and Carter (2006) have been replicated in the male population and contrary to expectations, Burnham (2010) noted no significant correlation between self-efficacy and paternal agency. Although this finding might be obscured due to the small sample used (N = 28), it still points to differences of experiences among genders.

The study by Kuhn and Carter (2006) has also been modified to explore differences in cognitions of mothers towards their child with autism and their typically developing child. Results of that study indicated that comparable levels of agency were reported for both children regardless of the condition (Meirsschaut et al., 2010), which might mean that agency level is a stable variable unaffected by the child's diagnosis.

Although parental involvement has been well studied, little is known regarding facts that could predict agency. This researcher has not been able to locate any other articles that analyze agency. Also, the few studies that mention the term only consider agency as a predictor of self-efficacy; no research, however, has been conducted to explore variables that could predict agency. Hence, the need to research it.

#### **Dispositional Optimism**

Dispositional optimism is the general expectation of good things happening. It refers to a favorable perception of life regardless of external circumstances, which is to say it is a trait that appears stable across time and context (Scheier & Carver, 1985). Dispositional optimism differs from domain-specific optimism; the latter refers to optimism towards a specific event/situation (Greenberg et al., 2004). For the purpose of this study, the researcher is considering dispositional optimism, expecting good things in life unrelated to the child and his/her condition.

It has been claimed that optimistic individuals tend to be confident and persistent even when facing challenges. They may take steps to deal with presenting problems sooner than pessimistic people. In other words, they do not simply believe that something can be achieved; they are also proactive to avoid the risks and do the most to achieve the goal (Carver et al., 2010). They expect good outcomes, but are cognizant that such

outcomes depend on their effort to pursuit them (Warter, 2009). This highlights the topic of this investigation; based on the information provided, it is logical to think that an optimistic parent would be more proactive to help his/her child. On the contrary, if a person doubts a goal can be achieved (pessimist), he/she may withdraw efforts to attain it (Carver et al., 2010).

Additionally, optimists report more social support, having larger friendship networks than their counterparts, which enable them to adjust better to stressful life events (Brissette, Scheier, & Carver, 2002). Research shows that optimists and pessimists differ in how they confront adversity, how well they cope with problems, and in their social and socioeconomic resources (Carver et al., 2010).

Optimism has been studied in a variety of setting, consistently proving to be a desirable trait (Carver et al., 2010). For instance, among cancer patients (N = 275), those with higher levels of optimism reported less anxiety, less depression, and higher health related quality of life than their counterparts (Zenger, Brix, Borowski, Stolzenburg, & Hinz, 2010). It is also interesting to note that optimistic spouses caring for their partners diagnosed with Alzheimer's disease showed better mental and physical health (Hooker, Monahan, Shifren, & Hutchinson, 1992).

Moreover, among parents of typically developing children (N= 212), those with higher levels of optimism, reported a more positive perception of the child's behavior and functioning than their pessimist counterparts (Heinonen et al., 2006). This is an important finding that would be interesting to replicate with parents of children with autism and other disabilities.

Parental optimism and autism. Optimism is a fairly new concept to be

researched in the field of autism. Up to now, the few studies that have explored the benefits of optimistic parenting through a standardized validated tool, have shown positive results (Baker et al., 2005; Ekas et al., 2010; Greenberg et al., 2004; Warter, 2009). For instance, in concordance with effects of optimism previously described, in a group of mothers of preschoolers with and without developmental delays, a positive relationship was established between optimism and parental well-being (Baker et al., 2005). Researchers also found that optimism moderated, but not mediated, the relationship between behavior problems and parental well-being (Baker et al., 2005)

Similar findings have been reached by others; mothers of children with ASD who report higher scores of optimism also report higher levels of social support, psychological well-being, positive effect, and life satisfaction (Ekas et al., 2010). Interestingly, the same benefits persist as the child becomes an adult; in fact, optimism is related to better mental and physical health in mothers caring for adults with autism (Greenberg et al., 2004). Researchers reported that the quality of the relationship with the adult child influenced maternal well-being; nonetheless, this effect was mediated by optimism and it was particularly strong for mother of individuals with autism compared to those caring for adults with Down syndrome or schizophrenia (Greenberg et al., 2004).

Another study (N = 207), concluded that greater levels of dispositional optimism predict greater satisfaction with the family's quality of life (Warter, 2009). Moreover, dispositional optimism and sense of coherence were found to mediate the relationship between perceived severity of the child's ASD and the family's quality of life; dispositional optimism also mediated the relationship between uncertainty regarding the child's condition and the family's quality of life (Warter, 2009).

Others have studied optimism as a coping mechanism and have identified that those parents who cope with the diagnosis by adopting an optimistic definition of the situation report lower levels of stress (Jones & Passey, 2005). It is important to point out, however, that no standardized tool was used to specifically measure optimism; instead, a self- report coping mechanism scale was distributed in which "adopting an optimistic view of the situation was a sub-category of the family coping mechanism along with maintaining family integration and co-operation (Jones & Passey, 2005). Indeed, more research on the trait with a standardized quantitative approach should be conducted.

The benefits of optimism when parenting children with autism, nonetheless, have been best illustrated by Durand et al. (2012). In an earlier study, a group of toddlers with cognitive and/or developmental disabilities and problem behaviors was monitored during 3 years. Surprisingly, regardless of the initial severity of the child's behavior, the best predictor of problem behaviors in follow up was a measure of parental optimism/pessimism (Durand, 2001). More strikingly, Durand et al. (2012) indicated that optimism can be taught, and it directly influences the child's behavior.

The authors in said study targeted parents with high levels of pessimism who had a child with a developmental disability who exhibited severe problem behavior. Families (N=35) were randomly assigned to a group that received a training program on positive behavior support (PBS) for 8 weeks or a group that included a combination of PBS training plus optimism training (Positive Family Intervention –PFI; Durand et al., 2012). Remarkably, children from families in the PFI group showed significantly greater decrease in behavior problems than the PBS only group.

Although findings pointing to optimism are highly promising, the pessimism

instrument used by Durand et al. (2012) measures pessimism directly related to immediate and future events associated with the child's condition, which would be considered specific optimism/pessimism. Therefore, the role and implications of parental dispositional optimism in the child's development is still unclear.

A different body of literature considering the measure of hope also highlights the importance of positive thinking. The concept of hope, closely related to optimism and researched under the positive psychology trend (Lloyd & Hastings, 2009), has been defined as the perceived capacity to develop conduits to desired goals and to motivate oneself to use those conduits (Snyder, 2002). Research indicates that mothers with greater hope worry less (Ogston et al., 2011); furthermore, hope was found to be a resilience factor for the well-being of mothers of children with autism and Down syndrome (Lloyd & Hastings, 2009).

Considering the numerous challenges explored earlier, it is fair to argue that under tremendous amount of stress, it could be difficult for some parents to adopt a proactive approach to aid in the development of child with ASD. Even so, according to the benefits of dispositional optimism reviewed here, optimism could predict the role parents adopt, and therefore a more in-depth investigation of the topic is warranted.

Some have claimed that researchers in the field of autism have given limited attention to personality traits (Baker et al., 2005), and have either pathologized the family and their experiences or ignored their possible role in impacting long-lasting positive change on the individual with the diagnosis (Warter, 2009). Along the line of positive psychology, it is time to move the attention from the illness to the process in which individuals can adjust and succeed even in times of crisis (Yates & Masten, 2004).

To the knowledge of this author, only four studies have considered the concept of dispositional optimism in parents of children with autism. Although it is known that optimism is beneficial for the well-being of the mother (Baker et al., 2005; Ekas et al., 2010; Greenberg et al., 2004) and for the family's quality of life (Warter, 2009), none of these studies integrated the concept of agency. As noted in this literature review, it is still unknown if expecting good things in life would lead to higher levels of assuming an active role for the child's development. The main purpose of this investigation was to bring light to that question.

### **Gap in the Literature**

Throughout this literature review, seminal work on agency (Kuhn & Carter 2006), has been cited numerous times. The reason being is that in the research conducted by this writer, only a few studies were located that explored the concept of agency in parents of children of autism as described above. In a similar manner, although dispositional optimism has been researched in numerous populations (Carver et al., 2010), limited studies have considered the trait among parents of children with autism. Combining the two variables (agency and dispositional optimism) in a study made it unique.

### **Theoretical Background**

To comprehend the grounds of this investigation, a major position needs to be highlighted: individuals have the ability to thrive even when facing adversity. As a proof of that, and related to the topic of this research, Bayat (2007) has shown evidence that a considerable number of families of children with autism function well and even become stronger as a result of having a child with a disability. This assertion has been well conceptualized through resilience theory, which is studied in the field of positive

psychology. In this segment, first a brief review of positive psychology is presented, followed by a description of resilience theory, which was adopted in this study.

Positive psychology. This represents a relatively new field within psychology that has been defined as "the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions" (Gable & Haidit, 2005, p. 103). A historical review of the field of psychology indicates that a great amount of research was conducted focusing on illness rather than in well-being. As Gable and Haidit (2005) explain it, the goal of psychology was to take the individual from minus eight to zero, rather than from zero to eight. A more balanced approach would include the understanding of how to relieve suffering, as well as how to increase happiness (Seligman, Steen, Park, & Peterson, 2005).

The relevance of this topic has been exemplified throughout the literature review that indicates that when parenting children with autism some marriages fail while others strengthen; some siblings misadjust, while others flourish; some mothers think of committing suicide while others find spiritual growth (Myers et al., 2009). It is clear that every story has two sides, and positive psychologists are aware of the pain and suffering in the world. The aim of this field, however, is to better understand how flourishing occurs. It is argued that such understanding is useful to assist those in crisis. Some of the topics studied in positive psychology are not completely new, however, since the beginning of the 21st century there has been an exponential growth of research, teaching and applications of positive psychology (Gable & Haidit, 2005; Wong, 2011). The new wave of positive psychology indicates that positive and negative interact with each other, therefore the need to understand this interaction. Along these lines, the study of resiliency

comes into play, which has also increased dramatically (Wong, 2011). Indeed, it is said that the four pillars of positive psychology are virtue, meaning, resilience, and well-being (Wong, 2011).

Resilience theory. Resilience has been defined as the process of adaptation within the context of significant adversity (Luthar, Cicchetti, & Becker, 2000). Hence, two main components surround this definition: exposure to significant threat and achievement of positive adjustment. In the situation studied here, those two components are met. First, considering the several challenges reviewed here, having a child diagnosed with autism can be considered a significant adversity. Second, a parent who adopts a proactive role is adjusting well to the situation.

According to this body of literature, wellness is not defined as something one has or does not have; but rather, as an ideal that can be accomplished by "moving the wellness curve toward a distribution with a greater pile-up of scores at the positive end and an asymptote at the negative end" (Cowen, 1991, p. 404). Hence, *protective factors* ameliorate the effects of adversity, while *risk factors* are linked to higher probability of maladjustment (Luthar et al., 2000). These factors include influences from the community, the family and the individual (Luthar et al., 2000; Yates & Masten, 2004). A short list of protective/risk factors includes: attachment bonds with caregivers and other adults, intellectual skills, self-regulation skills, positive self-perceptions, faith and hope, friends or romantic partners, bonds with community organizations, communities with services, and even cultures that provide positive standards, rituals, relationships and support (Masten, 2010). Furthermore, dispositional optimism, being researched here, is another protective factor likely to promote resilience adaptation (Grote, Bledsoe, Larkin,

Lemay, & Brown, 2007).

Interestingly, some argue that in most cases resilience does not require extraordinary resources but instead emerges out of "ordinary magic" (Masten, 2010), which means the natural interaction of systems that promote adjustment and development. It is claimed that resilience is not a trait, but rather it "is what happens when adaptive systems that have developed in the lives of individuals children, within themselves, their relationships, and their environments, work effectively to maintain or restore competence in development" (Yates & Masten, 2004, p. 526). Although numerous risks and protective factors have been identified, Yates and Masten (2004) argue that attempts to understand the process of resilience has only began. Cowen (1991) insists that wellness can be enhanced by natural or engineered protective factors; the challenge is to correctly identify such factors.

Indeed, a model of resilience in which a process of interaction of variables produces positive adaptation is more useful than a static traits model because the earlier allows for the investigation of such a process and a possible replication among at-risk populations. Hence, if optimism is a protective factor that leads to higher agency, it would then be ideal to train parents in acquiring a more positive view of situations, as Durand and his team have already done (2012). This goes along the empowerment model of intervention in the resilience framework in which strengthening of protective factors is promoted (Yates & Masten, 2004).

#### **Research Questions**

This study investigated the following questions:

**Research Question 1.** How does parental dispositional optimism affect the level

of parental agency as measured by Life Orientation Test- Revised (Scheier, Carver, & Bridges, 1994) and the Agency Questionnaire (Kuhn & Carter, 2006)? It was predicted that a correlation would be established between dispositional optimism and agency, in which optimistic parents do have higher agency than those scoring less in optimism. This relationship is illustrated in Figure 1.

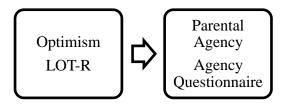


Figure 1. Parental optimism as predictor of parental agency.

Research Question 2. How does age of the child influence parental agency as measured by the Agency Questionnaire (Kuhn & Carter, 2006)? It has been reported that parents with younger children have higher frequency of communication with school personnel and greater involvement in the IEP process (Spann, Kohler & Soenksen, 2003). Although communication is only one component of agency, it is possible that a parent is more proactive when the child is younger. Therefore, the hypothesis for this question was that parents of younger children report higher agency than that of older children.

**Research Question 3.** How does educational level of the parents affect agency as measured by Agency Questionnaire (Kuhn & Carter, 2006)? It was expected that there is no relationship between educational level of parents and agency. The reasoning for this prediction is that the motivation to do the most for the child would be intrinsic and therefore unrelated to education.

**Research Question 4.** How do mothers and fathers differ in terms of optimism

as measured by Life Orientation Test- Revised (Scheir et al., 1994)? It was hypothesized that there is no relationship between gender and dispositional optimism. Since dispositional optimism has been defined as a personality trait (Carver et al., 2010), there is no reason to believe this would be different in males or females.

Research Question 5. How do mothers and fathers differ in terms of agency as measured by Agency Questionnaire (Kuhn & Carter, 2006)? It has been suggested that mothers are significantly more involved across all domains related to caring for a child (Burnham, 2010). Therefore the hypothesis for this question was that females would report higher agency than males.

**Research Question 6.** Which demographic variables show a significant effect on Agency Questionnaire (AQ) and/or the Life Orientation Test-Revised (LOTR) scores? It was expected that there is no relationship between any other demographic variables and agency or dispositional optimism.

### **Chapter 3: Methodology**

# **Participants**

This researcher collected and analyzed data from parents of children with ASD (*N* = 126) ages 18 and younger. Participation in the study depended on having a child who received a formal diagnosis of autism, Asperger's disorder, or PDD-NOS, which was verified through a question in the demographic section. Age limitation of the child was set at 18 years because it allowed the researcher to analyze differences in variables, specifically parental agency for younger versus older children.

Both mothers and fathers were welcomed and encouraged to participate in the survey. Usually, paternal participation in surveys is lower than that on mothers; for example, after extensive recruiting, Warter (2009) obtained a sample of 207 parents in which 90.8% were female and 9.2% male. Similarly, Burnham (2010) targeted fathers and was only able to collect data from a small sample (*N*=29); Burnham concluded that it was an extremely difficult population to reach. Correspondingly, as expected, a larger number of female responded to this survey; after excluding missing data, the total number of fathers was 12 and total number of mothers was 89.

Demographic information of the participants and the children is presented in Tables 1 and 2 accordingly and is reported as follows: the average age of subjects was 41 years, 65% reported being non-Hispanic white. In addition, 41% of subjects possess a bachelor's degree, 88% are married, the majority of respondents (23%) earn between \$60,000 and \$79,999 dollars, and 43% are employed full-time. In terms of demographics on children, the average age is 9 (SD = 3.97), 65% percent had a diagnosis of autism, and 80% are male, which coincides with gender rates in autism (CDC, 2012).

Table 1

Parent Demographic Characteristics

Variable	Level	Count	Percentage
Gender	Female	110	97.2
N = 126	Female	110	87.3
	Male	16	12.7
Race <i>N</i> = 124	White non-Hispanic	81	65.3
IV = 124	African American	6	4.8
	Asian American	1	0.8
	Hispanic or Latino	34	27.4
	Other	2	1.6
Education	High school	7	5.6
<i>N</i> = 126	Associate degree/ vocational/ professional certificate	16	12.7
	Some college	16	12.7
	Bachelor's degree	52	41.3
	Master's / Doctoral degree	35	27.8
Marital Status	Single	5	4.0
N = 126	Married	111	88.1
	Divorced/ Separated	10	7.9
Income Level	Under \$20,000	6	4.8
N = 124	\$20,000 - \$39,999	11	8.9
	\$40,000 - \$59,999	16	12.9
	\$60,000 - \$79,999	29	23.4
	\$80,000 - \$99,999	19	15.3
	\$100,000 - \$124,999	19	15.3
	\$125,000 - \$149,999	9	7.3
	Over \$150,000	15	12.1
Employment	Employed, full time	54	43.5
N = 124	Employed, part time	19	15.3
	Not employed, looking for work	4	3.2
	Homemaker	45	36.3
			50.5

Disabled, not able to work	2	1.6
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Table 2

Child Demographic Characteristics

Variable	Level	Count	Percentage	
Gender				
N = 122	Female	25	20	
	Male	97	80	
Diagnosis N = 122	Autism	79	65	
	Pervasive developmental disorder, not otherwise specified	24	20	
	Asperger's Syndrome	15	12	
	Not sure	4	3	

# **Sampling**

A convenient sampling procedure was used through online outreach. This was done in different ways. First, an invitation e-mail was sent to parents with whom this researcher has had personal contact. This researcher has worked privately in the field of autism providing floortime coaching to parents for the past 10 years; therefore, a number of parents (90) that include current and previous clients of this researcher, as well as other parents met during autism events in the community were invited to participate in the study.

In addition, this researcher is subscribed to a large online support group for parents and professionals about autism, consisting of around 1,800 members. In this group parents and professionals share information about different types of therapy, behavioral issues, and concerns with safety, school, siblings, and more. An invitation to participate in the study was posted there.

Social network sites were essential in recruiting participants. The link to the survey was posted in the professional Twitter account of this researcher that is currently followed by 405 parents and professionals in the field of autism. Likewise, the link was posted in the Facebook page of the investigator and was quickly shared by friends, professionals, and parents of children in the autism spectrum. Moreover, with the permission of the moderators, the link was also posted in different Facebook pages related to autism, such as The Autism Notebook Magazine, The Autism Society of Broward Ambassadors Group, The Interdisciplinary Council for Developmental and Learning Disorders (ICDL), and from there shared by many others in a snowball effect.

#### **Procedures**

**Design.** This study was conducted online and followed a quantitative explanatory design which is correlational and non-experimental. Several studies have followed the same quantitative approach to investigate similar topics related to parenting and autism (e.g., Benson, 2010; Dabrowska & Pisula, 2010; Ekas et al., 2010; Gau et al., 2012; Greenberg et al., 2004; Kuhn & Carter, 2006; Stuart & McGrew, 2009; among many others). Also, considering the hypothesis being tested and the availability of instruments to measure the variables, a quantitative approach seemed appropriate.

Moreover, currently, people spend a great amount of time on the Internet; and therefore, it was a convenient way to access participants. Regarding web-based surveys, results have been found to be equivalent to results from traditional survey methods (Gosling, Vazire, Srivastava, & John, 2004). For this type of study an online survey was suitable for several reasons. For instance, it is argued that the Internet has changed the way people interact with each other (Denissen, Neumann, & van Zalk, 2010). It provides

limitless opportunities for communication and an increased sense of anonymity. In this population, it is common that parents participate in online groups to connect with other parents and seek support; therefore, it seemed proper to reach out to them in that setting.

In addition, web-based research in social sciences is in the rise. Indeed, between 2004 and 2009, there was an increase of 534% of studies having at least an online component. It is an easy and economic way to access participants and it provides the anonymity that having the researcher in front would not provide (Denissen et al., 2010)

The initial invitation sent to the various databases discussed above introduced the researcher, the purpose of the study, and provided a link on www.surveymonkey.com to access the survey. A copy of this invitation is attached as Appendix A. Once parents accessed the link to the study, a consent form approved by the Institutional Review Board of the school (Appendix B) appeared, explaining in more detail the topic of the study; participation was voluntary, and there were no risks or incentives for filling out the questionnaire. Respondents had the option to stop participating at any time and all information collected was anonymous and confidential.

If parents decided to participate, demographic information was collected first including age, gender, ethnicity, educational level, and age of the child. For a complete copy of the demographic questionnaire see Appendix C. Afterwards, participants were to complete the agency and optimism questionnaires.

#### **Instruments**

This study measured dispositional optimism as the independent variable using the Life Orientation Test-Revised (LOT-R; Scheier et al., 1994) and agency as the dependent variable using the Maternal Agency Questionnaire (AQ) (Kuhn & Carter, 2006). Copies

of both instruments can be found as Appendix D. Table 3 presents a complete list of variables and measures.

Table 3
Study Variables and Measures

Variable	Instrument	Number of items	
Demographics	Demographic questionnaire	10	
Optimism	Life Orientation Test-	10	
	Revised		
Agency	Paternal Agency	20	
	Questionnaire		

Note. N=40

**Life Orientation Test-Revised.** The Life Orientation Test was first developed in 1985 (Scheier & Carver, 1985) to measure dispositional optimism. A revised version was issued in 1994 consisting of 10 items, 4 of which are fillers, not counted towards the optimism score, and of the remaining 6, 3 are worded in positive and 3 in negative terms. Respondents are asked to express the extent of agreement using a 0 to 4 scale, 0 being *strongly disagree* and 4 being *strongly agree*. The three items worded negatively are reversed before scoring. Total scores range from 0 to 24 (Scheier et al., 1994).

Internal consistency has been reported with a Cronbach's Alpha of 0.78. Test-retest reliability scores are 0.68 after 4 months, 0.60 after 12 months, 0.56 after 24 months, and 0.79 after 28 months (Scheier et al., 1994). In a different study (Hirsch, Britton & Conner, 2010), internal consistency was ( $\alpha = 0.69$ ) at baseline and ( $\alpha = 0.72$ ) at follow up. A strong criterion validity was reported, showing a negative correlation with hopelessness (r = -0.65, p < .001) and depression (r = -0.60, p < .001). Surprisingly, in this study Cronbach's Alpha was only 0.36.

The LOT-R is well recognized and has been used widely in a variety of populations such as college students (Brissette et al., 2002), spouse caregivers (Hooker et al., 1992), and cancer patients (Zenger et al., 2010) among many others (Carver et al., 2010). Permission to use the tool was granted by the authors via e-mail.

Parental Agency Questionnaire. Although the instrument is originally called Maternal Agency Questionnaire, none of the items are specifically related to gender, therefore in this study it is referred to as Parental Agency Questionnaire or AQ and was distributed to both mothers and fathers. This scale has already been used among males (Burnham, 2010).

This tool was developed as part of a parental cognitions construct analyzed in relationship to self-efficacy (Kuhn & Carter, 2006). It consists of 20 questions answered in a 1 to 5 scale, 1 being *never* and 5 being *always*. Scores are summed to obtain a total score ranging from 20 to 100. The authors of the scale do not instruct to reverse any item or that the scale contain any fillers; for the purpose of this study, however, one of the items was not counted towards the final score since, according to clinical experience, the item would need to be reversed. Question 10 reads as follows: "How often do you let professionals 'who know best' (school officials, pediatricians, psychologists) decide on your child's education plan and medical intervention?" Based on conversations with parents, a caregiver who is deeply involved does not allow others to make decisions without consulting various professionals, researching on their own and using their critical thinking skills. For this question to be valid, it is assumed that the score would have to be reversed; nevertheless, considering that the authors do not provide such instructions (Kuhn & Carter, 2006), it was decided to delete this question. Therefore total scores

range from 19 to 95.

Kuhn and Carter (2006) reported the necessity of the new scale to measure the concept of agency. Authors accounted an internal consistency of 0.79 having distributed the questionnaire to 170 mothers. In this study AQ had a strong reliability of 0.89. A stronger reliability (0.924) was reported in a sample of fathers (Burnham, 2010). In the original investigation, to examine incremental validity, agency was analyzed in comparison to other variables studied, namely guilt and autism knowledge. Results produced a statistical significant correlation. (0.21 and -0.20, respectively). It is claimed then that agency is related to both guilt and autism knowledge but represents a construct on its own (Kuhn & Carter, 2006).

The sample used by Kuhn and Carter (2006) consisted of mothers of children ages between 2.4 and 10.8 year. In the present investigation, the questionnaire was distributed among mothers of children up to 18 years old; it was assumed that this would not be an issue as the wording of the questions applies to older children as well. For instance, Question 9 reads: "Provide feedback to your child's Early Intervention or school team about progress?"

This writer made three attempts to communicate with the authors of the scale to request permission to use it; unfortunately, no reply was obtained. The scale was published in the American Journal of Orthopsychiatry; therefore, it was used considering it to be public domain.

#### **Data Collection and Analysis**

Data for each research question were collected and analyzed as follows:

Research Question 1. How does parental dispositional optimism affect the level of parental agency as measured by Life Orientation Test-Revised (Scheieret al., 1994) and the Agency Questionnaire (Kuhn & Carter, 2006)? To answer this question data were gathered for a total score from Questions 1, 3, 4, 7, 9 and 10 on the LOT-R. As per instrument instructions, Items 3, 7 and 9 were reversed prior to scoring; and Items 2, 5, and 8 were ignored (Scheier et al., 1994). In addition, a total score from all the questions in the Agency Questionnaire, with the exception of Item 10 was used (See Appendix D). Total numerical scores from the LOT-R and the Agency Questionnaire were first preliminarily analyzed through a scatter plot diagram; then, Pearson r correlation was used to show whether or not a relationship between the variables exists.

Research Question 2. How does age of the child influence parental agency as measured by the Agency Questionnaire (Kuhn & Carter, 2006)? Total scores from the Agency Questionnaire and Question 9 from the demographic questionnaire were used (See Appendices C and D). To answer this question, the same procedure was used as Question 1. First scatterplot diagram and then Pearson r.

Research Question 3. How does educational level of the parents affect agency as measured by Agency Questionnaire (Kuhn & Carter, 2006)? Item 4 from the demographic section (Appendix C) and total scores from agency questionnaire (Appendix D) addressed this question. A non-parametric ANOVA test was used to answer the question.

**Research Question 4.** How do mothers and fathers differ in terms of optimism as measured by Life Orientation Test- Revised (Scheir et al., 1994)? Total scores from

LOT-R and Item 1 from the demographic questionnaire were utilized here (Appendices C and D). To analyze this question a non-parametric *t* test was used.

**Research Question 5.** How do mothers and fathers differ in terms of agency as measured by Agency Questionnaire (Kuhn & Carter, 2006)? Data to analyze this question were collected from the total scores from the agency questionnaire and Question 1 in the demographic section (Appendices C and D). It was then answered through a non-parametric *t* test.

Research Question 6. Which demographic variables show a significant effect on Agency Questionnaire (AQ) and/or the Life Orientation Test-Revised (LOT-R) scores? Total scores from the LOT-R and AQ and questions from the demographic section were used to answer this question (Appendices C and D). Two general linear models were created to answer this question.

#### Timeline

A proposal of this investigation was submitted to the Applied Research Center (ARC) of the university for review in early June of 2013. Once revisions were made and approval was granted, the document was sent to the Institutional Review Board (IRB). Only after IRB approved the proposal was the study implemented. In early July of 2013, online outreach began as detailed above. Data collection lasted 3 weeks.

#### **Confidentiality**

All the data gathered in the study remain confidential. Once participants accessed the link to the website, the researcher collected no information that could reveal their identity; therefore, data were anonymous. Results of the study were imported from the website in a SPSS file for analysis. If participants wanted a copy of the results they were

invited to e-mail the researcher; there was no way to link the responses to the identities of participants.

#### Limitations

Although the study aimed to include a representative sample of the population, parents who are subscribed to some type of database or social network group have already showed a proactive approach to do more for the development of their child. Some have argued that parents who volunteer to complete surveys have different characteristics than those who do not volunteer (Osborne & Reed, 2010; Stuart & McGrew, 2009). Therefore, this may limit the external validity of the results and the generalizability of the findings (Meadan et al., 2010). Moreover, a true representative sample of the population would include a much larger number of participants as presented in the power analysis below (see Table 4).

Table 4

Power Analysis for Each Research Question

Research questions	Statistic	Tails	Effect size	Alpha	Power	Sample size
1	Correlation	2	0.02	0.05	0.80	2,000 Total
2	Correlation	2	0.09	0.05	0.80	966 Total
3	ANOVA	2	0.17	0.05	0.80	420 OR 84 per group
4	t-test	2	0.16	0.05	0.80	420 OR 84 per group

5	t-test	2	0.79	0.05	0.80	42
						OR
						21 per group

Also, it is possible that a parent would feel shame or guilt in accepting lack of involvement in assisting their child as Kuhn and Carter (2006) reported; therefore, this could lead to parents not providing valid responses. Another deficit of this study is that only self-report instruments were used, which may lead to socially desirable responding tendencies. It is also important to point out that no tool was used to confirm the diagnosis of the child.

### **Chapter 4: Results**

It is not known if dispositional optimism plays a role in the level a parent becomes proactive in the development of the child in the autism spectrum; the purpose of this investigation was to bring light to that inquiry. To do this, as explained in the previous chapter, two instruments, to test optimism and agency, were distributed to a group of parents (N = 126). In this chapter, detailed information regarding statistical results of each research questions is presented. Level of significance for all questions was set at 0.05.

### **Research Question 1**

How does parental dispositional optimism affect the level of parental agency as measured by Life Orientation Test-Revised (LOTR)? Total numerical scores from the LOT-R and the Agency Questionnaire were reviewed through a scatter plot diagram (Figure 2). Pearson's correlation was used to quantify this relationship. Contrary to expectations, results show no significant correlation between the two variables r(101) = 0.01, p = 0.854.

In an attempt to understand whether or not this relationship existed among parents of younger children, another Pearson correlation was calculated between LOT-R and the Agency Questionnaire for parents with children ages 5 or lower. Again, results show a non-significant correlation between the two variables r(23) = -0.08, p = 0.687.

#### Research Question 2

How does age of the child influence parental agency as measured by the Agency Questionnaire (AQ)? Total numerical scores from the Agency Questionnaire and child's age were reviewed through a scatter plot diagram (Figure 3). Pearson's correlation was

used to quantify this relationship. Results show no significant correlation between the two variables r(101) = -0.09, p = 0.356, which means that agency is unrelated to age of the child.

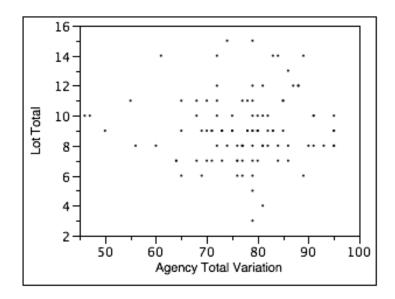


Figure 2. Scatter plot of Life Orientation Test-Revised score with agency total score.

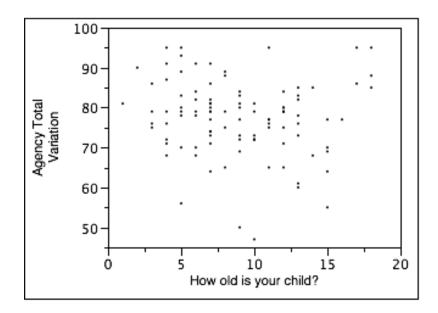


Figure 3. Scatter plot of agency total score with child's age.

### **Research Question 3**

How does educational level of the parents affect agency as measured by Agency Questionnaire (AQ)? Frequency distribution indicates variation in sample sizes with only five subjects possessing a high school diploma. Therefore, a Kruskal-Wallis test was conducted to evaluate differences among the five educational groups (High school, associate degree/ vocational/ professional certificate, some college, bachelor's degree or master/doctoral degree) on the median Agency Questionnaire score. The test, which was corrected for tied ranks, was not significant  $\chi^2(4, N = 124) = 2.04$ , p = 0.728. In other words, as expected, educational level was not related to agency. Descriptive statistics are presented in Table 5.

Table 5

Descriptive Statistics for Agency Questionnaire by Educational Level and Gender

Variable		N	Median	Min	Max
Educational					
Level	High school	5	80	50	84
	Associate degree/ vocational/ professional certificate	13	77	46	86
	Some college	14	77	47	95
	Bachelor's degree	42	79	64	95
	Master's /doctoral degree	28	77	55	95
Gender					
	Male	12	71	47	89
	Female	90	79	46	95

### **Research Question 4**

How do mothers and fathers differ in terms of optimism as measured by Life Orientation Test-Revised (LOTR)? The median LOT-R score for males is 9.5 (range of 3–15) and females 9.0 (range of 4–15). Using a non-parametric Wilcoxon test no significant difference was found between mothers and fathers z=0.22, p=0.822. A non-parametric test was used because the LOT-R uses ordinal data to create a subject's score. Descriptive statistics are presented in Table 6.

Table 6

Descriptive Statistics for LOT-R by Gender

Measures	Female	Male
N	99	14
Mean	9.24	9.71
SD	2.12	3.47
Median	9.0	9.5
Min	3	4
Max	15	15

## **Research Question 5**

How do mothers and fathers differ in terms of agency as measured by the Agency Questionnaire (AQ)? Females had a median score of 79 (range of 46–95) and males had a median score of 71 (range of 47–89). Using a non-parametric Wilcoxon test a significant difference was found between mothers and fathers z = -2.38, p = 0.017. A non-parametric test was implemented because the AQ uses ordinal data to create a subject's score. Results show that females possess a median AQ score 8 points higher than males. Descriptive statistics are presented in Table 5.

Table 7

Recoded Demographic Characteristics

Variable	Level	Count	Percentage
Race			
N = 124	White, non-Hispanic	81	65.3
	Other	43	34.6
Education N = 126	Some college or less	39	30.9
N = 120	College degree	87	69.0
Marital Status	Married	111	88.0
N = 126			
	Other	5	11.9
Income Level	\$59,999 or less	33	26.6
N = 124	\$60,000 - \$99,999	48	38.7
	\$100,000 or more	43	34.6
Employment	Employed, full time	54	43.5
N = 124	Homemaker	25	20.1
	Other	45	36.2
Diagnosis	Autism	79	64.5
	Other	43	35.2

# **Research Question 6**

Which variables show a significant effect on Agency Questionnaire (AQ) and/or the Life Orientation Test-Revised (LOT-R) scores? To better understand the relationship between the demographic variables (a) parent's age, (b) child's age, (c) race, (d) educational attainment, (e) marital status, (f) income level, (g)employment, (h) child's diagnosis, (i) adult's gender, and (j) child's gender, and the two outcome measures LOTR and AQ, two general linear models were created. However, before the model could be

created, race, educational attainment, marital status, income level, employment, and child's diagnosis were recoded into dichotomous variables for better interpretation. Table 7 provides a description of the recoding. Results show the following: (a) There is a significant effect of non-white females on AQ after controlling for the effect of all other demographic variables, F(12, 82) = 2.41, p = 0.009, non-white females possess the highest AQ score of 11.20 (1.83); (b) There is a significant effect of non-white subjects with a college degree on LOTR after controlling for the effect of all other demographic variables, F(12, 93) = 2.00, p = 0.032, non-white subjects with a college degree possess the highest LOTR score of 83.94 (7.04).

### **Chapter 5: Discussion**

Statistical analysis should not be interpreted without a narrative discussion of the results and possible limitations that could have affected the accuracy of those results. In this final chapter, first a brief overview of the study is presented, followed by an elaboration and interpretation of results; implications, limitations and recommendations for future research are offered.

#### Overview

Several studies have concluded that raising a child with autism can indeed be difficult and stressful (e.g., Dabrowska & Pisula, 2010; Griffith et al., 2010; Hoffman et al., 2009). Nonetheless, active involvement of the parents in the development of the child, also referred as agency, is important and beneficial not only for the children but for the parents as well (Meadan et al., 2010; National Research Council, 2001). Given this, the researcher aimed to identify whether or not there was one specific variable that would significantly impact agency.

A literature review of the topic found dispositional optimism to be a desirable trait that serves as a protective factor in times of crisis (Carver et al., 2010). The few studies that have explored dispositional optimism among parents of individuals with autism have highlighted its benefits. For instance, dispositional optimism is related to parental mental well-being (Baker et al., 2005; Ekas et al., 2010; Greenberg et al., 2004), life satisfaction, and quality of life (Ekas et al., 2010; Warter, 2009).

Hence, the main purpose of the study was to determine if dispositional optimism was indeed a predictive variable to agency. Contrary to expectations, results from this study failed to establish this relationship. Other findings, however, were drawn from the

data analyzed. For example, it was established that females score higher in agency than males; also, agency was found to be unrelated to parental education level or age of the child. Moreover, agency was found to be higher among female non-white participants, and optimism was unrelated to gender and associated with non-white participants who had a college education and above. Results will be discussed in light of past research studies.

# **Dispositional Optimism and Agency**

The first and main research question this study explored had to do with a possible relationship between agency and dispositional optimism. Opposing the prediction, no correlation was found between the variables. Nonetheless, before disregarding a positive influence of optimism on agency, certain arguments must be considered about this question and the methodology used.

Indeed considering the literature reviewed on dispositional optimism and agency, one could assume that there is a positive relation between the two variables. Surprisingly, data from this study do not support this assumption. One of the possible explanations for this negative result has to do with the sample size used. As presented in the power analysis in Chapter 3 (Table 4), an appropriate sample size to establish this relationship would be 2,000 participants, which is much larger than the one gathered in this investigation; therefore, results should be considered with caution.

Moreover, there are other issues that need to be discussed. To begin with, while collecting data, this researcher received comments from parents regarding a possible misinterpretation of results based on the questions asked in the AQ. As explained by a mother:

I felt some of my answers to questions, while honest, might have led one to reach the wrong conclusions. For example, when asked if I educate family members about autism—in real life it's a mixed bag—my brother's family has their own child with autism, so they certainly do not need education from me! My other brothers are teachers, so while I can talk about things with them, I wouldn't really consider that educating them.... As to discipline, we never discipline our son because he never does anything bad, not that we don't believe in discipline or cave in or something. He is rather naive and doesn't really have the scheming gene. He still mentally beats himself up for the one lie he told to us when he had cut his own hair at school and blamed it on another child. We didn't even punish him for that, he beat himself enough for it, and everyone cuts their own hair as a child. Someone with those types of sensitivities, and high safety consciousness isn't really getting into a lot of trouble. (S. Painting, personal communication, July 13, 2013)

The comments from this mother point to possible issues related to the validity of the agency questionnaire, at least for some parents. In the case of this mother, considering specifics of her situation, the fact that she does not educate family members (Question 16 in AQ) or that she does not discipline her child (Question 2 in AQ), are not accurate indicators that she is not being proactive and doing the most for the development of her child. In other words, even though the instrument had good internal reliability, without considering the individual differences each family faces, some of the questions may not be valid. Evidently, this could have impacted the results.

A further attempt was made to analyze this question including only parents of children ages 5 and lower. It was considered that the AQ instrument would be more valid among parents of younger children for several reasons. For example, a parent of an older child may not attend conferences about autism (Question 13 in AQ) or read books about it (Question 11 in AQ) as frequently as he did in the past because he has already gained greater knowledge of the condition as compared to the earlier years of the child's diagnosis. In a similar manner, the same applies to educating family members (Question16 in the AQ). It is possible that a parent provided a great deal of information to

the extended family when the child was younger and may not see it necessary or appropriate to continue doing so, some years after the diagnosis. It was hypothesized then, that the instrument would accurately capture behavior of parents of younger children as opposed to older ones.

Nonetheless, even calculating only the responses from parents of younger children, a relationship between dispositional optimism and agency could not be established. Hence, supposing that the agency questionnaire is completely valid across age of the child, would it be possible that some parents wanted to portray a specific self-image and therefore their responses were not accurate? This could be a possibility, at least for dispositional optimism, revealed by the low reliability of the scale obtained in this study.

Another possibility to consider is whether some parents are trapped in a blind optimism and therefore do not take action to do the most for child. This is to say, they trust that the goals will be met, they do expect positive outcomes, and therefore think they do not need to be proactive, as positive results will be achieved. According to Carver et al. (2010) that cannot be correct, as people with high optimism do not merely believe that something good will happen and sit waiting. In fact, it is argued that there is a difference in the way optimists and pessimists approach problems; indeed, people who believe a goal can be attained will persevere even when facing misfortune and when progress towards the goal is slow. On the other hand, those who doubt a goal can be reached may not even make an effort to accomplish it (Carver et al., 2010). In this sense, optimists have a sense of confidence in the fact that they can successfully undertake their goals, while pessimists suffer from doubt and hesitation. This can be explained by the

coping mechanisms used by each group: optimists adopt engagement coping and problem solving mechanisms while pessimists disengage and fall into denial (Carver et al., 2010).

It appears, then, that a component of agency is implied in the construct of dispositional optimism; yet, not considered in its scale. Interestingly, hope, which is closely related to optimism, specifically involves in its definition the concept of agency. Therefore, a closer review of this constructs is necessary.

Optimism versus hope. Hope is defined as "the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways" (Snyder, 2002, p. 249). Thus, this concept has three requirements: the ability to set goals, pathways thinking, and agency thinking. Pathways thinking is understood as the production of plausible routes towards the goal, with a sense of confidence about the success of the route. The person, who enjoys high hope, and therefore high pathways thinking, will also develop alternate routes towards the goals and adapt those routes in the process. Agency thinking, in this theory, is described as the perceived capacity to use the pathways to reach the goals, which is the motivational aspect of hope. It involves mental energy, and self-talk to continue using the pathways. This last component is clearly important when facing difficulties (Snyder, 2002). A scale was created by Snyder et al. (1996) to quantify that definition.

In summary, for hopeful thinking to be present, a person should be active to create the pathways to reach the goals and be motivated and confident to use those pathways (Snyder, 2002). If this is the case, a study analyzing hope with the definition previously presented, and using the hope scale by Snyder et al. (1996) would be likely to establish a correlation with agency in parenting children with autism. To the knowledge of this

researcher, a study with those variables has not been conducted.

What is known about hope in parents of children with autism is limited and similar to that about dispositional optimism. For instance, in a group of 138 mothers and 58 fathers raising children with intellectual disabilities, hope was considered as a psychological resiliency factor (Lloyd & Hastings, 2009). Unsurprisingly, both components of hope, agency and pathways, were significantly correlated with maternal well-being. For fathers, agency and pathways were negatively related to anxiety and depression, and positively associated with positive affect (Lloyd & Hastings, 2009).

In addition, a different study established a negative correlation between hope and worry (Ogston et al., 2011). In a sample of parents of children with autism (n = 60) and parents of children with Down syndrome (n = 199), mothers with higher levels of hope report less worry. Definitely a person can become more active if worry is not a burden (Ogston et al., 2011). In such situations, energy and time spent worrying is wasted instead of using it to act. It is important to highlight, however, that this study used a much larger group of parents of children with Down syndrome than those of children with autism; in addition, this study used a version of the Hope Scale that measures hope specifically related to a challenge, in this case, the raising of the special child. It would be interesting, however, to analyze the role of dispositional hope when parenting a special child.

Moreover, it is also known that there is a relationship between hope and parenting sense of competence (Carol, 2007). In a group of 82 mothers of children with autism, the researcher studied spirituality and hope as predicting variables to maternal sense of competence. Results from the study indicated a correlation between hope and sense of competence, but not spirituality. Again, Carver et al. (2010) have indicated similar

findings about optimism, which is that people with high optimism have strong beliefs in the effectiveness of their actions.

Comparing hope to the definition of dispositional optimism, there remains the probability that a person expects positive outcomes without engaging in proactive behavior to meet those expectations. Although a component of agent is implied in the description of dispositional optimism, it is not directly articulated and included in the LOT-R scale.

In any case, the benefits of optimism in parents of children with autism have been clearly presented by Durand et al. (2012). Considering optimism specifically related to the condition of the child, this trait was the major predictor of child development. In Durand et al.'s 2012 study, pessimistic parents receive training on optimism regarding the child and his/her challenges, as well as positive behavior training. Children whose parents participated in both trainings improved significantly in reduction of problem behavior, as compared to those whose parents only trained in positive behavior intervention. Durand et al.'s 2012 study presents findings that could strikingly shift service provision. Indeed, for professionals in the field, this would imply that a great deal of attention should be geared to aiding the parents to paraphrase challenges with a positive attitude. As a result a professional would help parents change statements such as "my child cannot do that" to "my child is not ready yet, we are still working on that." Nevertheless, optimism is a topic that has not been studied in depth in the population of parents of individuals in the spectrum. This investigation aimed to contribute to that deficit.

Although this study failed to establish a relationship between dispositional optimism and agency, considering the discussion presented, it is concluded that the

answer remains unclear and further attempts should be made to better understand a possible interaction between the two variables. Indeed, a future study to better understand the topic should be conducted addressing the limitations and recommendations detailed later in this chapter.

### Agency and Age of the Child

The second research question aimed to clarify if age of the child affected the level of agency. No relationship was established between those variables. Although, to the knowledge of this researcher, no study has specifically analyzed the same measures, researchers that have considered similar topics have yielded contradictory outcomes. For instance, opposing current findings, some have reported that parents of younger children have higher frequency of communication with school personnel and greater involvement in the IEP process (Spann et al., 2003); which could be interpreted as parents of younger children who probably were recently diagnosed are more involved, and as the child grows older a lower level of involvement emerges.

In a similar manner, among typically developing children, researchers have claimed that involvement generally decreases by grade level (Green, Walker, Hoover-Dempsey, & Sandler, 2007). In said study, school and home involvement was analyzed among parents of children in first grade through sixth grade (N = 853). Predicting variables included motivational beliefs about involvement, perceptions of invitations to involvement, and life context. Regardless of the variables, involvement decreased as the child grew older. Here, nonetheless, it is important to consider that a typical child needs independence as he transitions from childhood to adolescence and beyond (Green et al., 2007), and therefore may not require the same level of parental involvement as a younger

child with a disability may need.

In fact, an interesting point to consider is whether agency should be measured differently according to the age of the child. Indeed, one could assume that as the child grows, the needs of the family and the child also change, and therefore behaviors that represent agency may be different. This issue was discussed in detail in the previous section regarding the validity of the agency questionnaire across age of the child, which is to say that some of the questions in the AQ may not be accurate descriptors of agency for parents of older children.

In any case, in this research question the underlying topic is whether or not agency is a stable trait and therefore does not change over time. Related to this is the finding by Meirsschaut et al. (2010) that indicated that mothers report equivalent levels of agency in the development of the child with ASD and the typically developing sibling as well. Therefore, a non-active mother of a typically developing child is likely to keep the same low level of involvement with the sibling with a developmental disability, and vice versa.

Results from this study indicate that agency behavior is unrelated to age of the child. Therefore, considering agency to be a stable trait over time, a parent will continue to have consistent level of involvement as the child grows, however in a different way, which depends on the changing needs of the child. Behaviors that indicate agency will be modified to fit the emerging needs of the individual with the disability and the family.

If agency is indeed a variable stable over time, a further question to examine is: how can a professional aid in improving agency, if that is even possible? Regarding this, Benson et al. (2008) have highlighted that open communication and support from

teachers and professionals is a predictor of involvement. Keeping this in mind, teachers and other professionals in the field should make an effort to help parents feel comfortable about expressing their concerns and thoughts about the child's development. This type of involvement would be initiated by the school or therapeutic center as defined by Epstein (1996); the question that remains is how to help parents increase self-initiated practices, which have greater impact on the child's education (Epstein, 1996).

### **Agency and Demographic Variables**

Although the main interest of the researcher was to explore agency in terms of parental dispositional optimism, other exploratory analyses were conducted to better understand whether or not any other demographic factors could have an impact on agency.

**Education.** Research Question 3 investigated whether or not the level of parental education could have an effect on agency, which is to say that educated parents are more proactive than those with less education. One could quickly jump to make such an assumption. Findings from this study suggest that this is not the case; as expected, there is no relationship between parental education and agency.

This finding contradicts those from Harstad, Huntington, Bacic, and Barbaresi (2013) that indicated that maternal education level is associated with receipt of IEP; in other words, children of mothers with an education of high school and above are more likely to receive special education services than those of mothers who have not completed high school. Moreover, similar findings have been reached by others. In a study of parents of elementary and middle-school students developing typically, researchers analyzed a number of variables that could predict involvement, such as

motivation, perception of involvement, and socioeconomics. Results indicated that the socioeconomic predictor of school-based involvement was indeed parental education, although the same was not true for home-based involvement (Green et al., 2007). A possible explanation of this is that parents with low education may feel intimidated to engage in the school setting, but may not have the same obstacle at home.

Indeed, the concept of agency constitutes a variety of behaviors and although advocating for services may be more viable for educated mothers, other agency behaviors like engaging with the child and setting play dates may not require high level of education, which could explain findings from Hartad et al. (2013) and Green et al. (2007). Still, it is important to consider that most of the population in the study had education of college and beyond (69%), and all of the participants have completed high school, which may have affected the generalizability of the results. A reader may ponder if results would have been different if the sample also included less educated participants. One could also consider if those who decided to take part on the research were only those who have acquired some level of education.

Gender. Research Question 5 drew a significant and expected finding confirming that mothers of children with autism report higher agency than their male counterparts. Traditionally in raising children, gender roles are different with females being expected to take most of the responsibility in this department, even if employed outside of the homes (Gray, 2003; Konstantareas & Homatidis, 1992). It is not surprising that Burnham (2010) reported that females are significantly more involved across all domains related to caring for the child.

It appears that many parents leave the responsibility to the mothers, and rest

assured that the needs of the child are being met. When collecting data, this researcher received an inquiry from a father asking if he should answer the questions based on his behavior or that of the family. As it is, even though he did not directly read books or set play dates, it occurred within the family system through the behavior of the mother.

As it is expected, such a responsibility may cause burden on the mother; therefore, it is not surprising that mothers report higher levels of distress and depression (Dabrowska & Pisula, 2010; Jones, Totsika, Hastings, & Petalas, 2013). Some suggest that this is related to the experience mothers are having compared to their partners; indeed in a qualitative study on the topic a father explains:

Nine times out of ten it's the mother who is [caring for the child] day after day, hour after hour. A lot of the burden tends to be put on the mother because the father is working. The father essentially has respite care five days a week. (Gray, 2003, p. 635)

In the same study, the authors report that often times fathers become extracommitted to their work and therefore have low involvement in the child's development;
commonly, fathers see themselves as providing emotional support for their wives instead
of being directly involved with the children's therapies or education (Gray, 2003).

Considering this, results from this question imply the importance for professionals to be
sensitive and aware of the well-being of the mothers. Indeed, one cannot expect a person
to be actively involved in therapies and education if her mental health needs are not met
and/or she is in a depressed state.

Evidence of the lower paternal involvement is also revealed in the deficit of male participation in research studies; some have concluded that fathers of children with autism are a very difficult population to reach (Burnham, 2010; Warter, 2009). Indeed, after aggressive outreach, still only a few parents agree to participate (Burnham, 2010;

Warter, 2009). This study experienced the same difficulty; in fact, the percentage of male participation was only 12%.

Race. Research Question 6 was exploratory in nature and aimed to establish what other variables if any would affect either results from the agency or optimism results. Analysis indicated that non-white females had the highest agency scores after controlling for other variables. As per the discussion above, it is not surprising that the female agency score is higher than that in males; nonetheless, it was unexpected to establish differences across races.

Regarding this, Harstad et al. (2013) reported that children with autism of Hispanic mothers are less likely to receive an IEP for special education services than any other racial group. Also, when studying service provision across races, it has been identified that African American children receive autism diagnosis 1.5 years later than the diagnoses of the White group (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Moreover, other researchers suggest that racial and ethnic minorities consistently receive a lower quality of interpersonal attention in the health care setting than their white counterparts (Cooper, Beach, Johnson, & Inui, 2006). These findings point to the negative experiences minority families go through, becoming victims of the system; researchers call on professionals to advocate for appropriate services for these families (Harstad et al., 2013).

This, however, does not necessarily mean that parents of ethnic minorities are not as proactive in the development of the child as the white majority. Although the findings in this study may be surprising considering the literature reviewed, it is also possible to explain them through resiliency theory. In other words, an ethnic minority parent may go

through a negative experience in the health care system trying to access services; therefore, they may be more strongly driven to engage in agency behaviors on their own. This researcher was unable to locate other studies that found similar findings regarding non-white parents being more proactive.

#### **Dispositional Optimism and Demographic Variables**

Exploring the details of how optimism works was not a main purpose of this investigation; in fact, other researchers have already studied that topic deeply (Carver et al., 2010). Nonetheless, the researcher considered the optimism variable as it relates to demographic fact. Those results are discussed in this segment. First, the gender variable was explored in terms of its influence on dispositional optimism. A further analysis was conducted to identify if any other variables were important to this trait.

Gender. Research Question 4 aimed to indentify whether or not there was any difference in levels of dispositional optimism between mothers and fathers. As expected, no relationship was found, which indicates that dispositional optimism is a trait unaffected by gender. Other researchers have concurred (Srivastava, McGonigal, Richards, Butler, & Gross, 2006); in fact, in an optimism study of 108 couples, the mean LOT score for females and males was almost identical (Srivastava et al., 2006). An extensive literature review on dispositional optimism also suggests no evidence of disparity on gender (Carver et al., 2010). Dispositional optimism has been described as a personality trait, which is somewhat stable over time; the studies reviewed for this investigation do not point to any difference in manifestation between males and females.

**Race and education.** A further finding from Research Question 6 in regards to optimism is that non-white subjects with a college degree have higher scores than any

other group after controlling for all other demographic variables. Education status may be related to optimism; however, this relationship can be explained in conversely, which is to say optimism influences the determination of individuals to pursue education. In a study by Solberg Nes, Evans, and Segerstrom (2009), the LOT-R was administered first-year college students; a year later, the optimists were more likely to continue their studies, while those with lower optimism were more likely to drop out of school. In this study those with a college degree also had higher optimism. Regarding this, again, similar findings have been established with the hope scale. In the study by Ogston et al. (2011) mothers who reported higher levels of hope were more educated than those with lower levels of hope.

In addition, it is interesting to note that this category of optimists specifically included non-white subjects. Regarding race, most of what is known about optimism comes from studies of North Americans mostly of European descent; and it appears that there is no clear distinction in this regards. Hence, it is difficult to recognize whether or not this trait occurs in a different way among cultures/races (Carver et al., 2010). Some researchers have speculated (Chang, Asakawa, & Sanna, 2001) that cultural differences between the East and West influence optimism and pessimism. To understand the differences, researchers asked European American and Japanese students to rate the likelihood that a future positive or negative event would occur to self and others. Results indicated that Japanese were more likely to expect good things to happen to others than to self; European Americans predicted positive events happening to them and negative ones occurring to others (Chang et al., 2001). Those findings point to different manifestations of optimism and pessimism based on cultural influences of collective versus

individualistic behavior. Although in this study there was not a marked difference between Eastern versus Western participants to compare with Chang et al. (2001), results from the present study indicate a possible pattern among non-white individuals; this is, though, a subject that requires further research.

#### Limitations

The study of parenting children with autism diagnoses is a very complex issue. In the present investigation, the researcher was primarily looking to analyze the role of a particular variable, namely dispositional optimism affecting agency. While conducting the study, however, some issues related to the agency questionnaire came to surface. As discussed above, it is not clear if the scale is a valid indicator of agency for every family. Besides the issues previously described, there are other points worth mentioning.

For example, a mother known by this writer claims that she does not participate in any groups or the like related to autism because in those groups parents are usually very negative. She declares that many parents persist in talking about the negative things of having a child in the spectrum, and she has preferred to stay out of the drama. Hence, even though she is not involved in the autism community, she actively attends to the needs of her child. In her case, Question 12 from the AQ that reads: "How often do you communicate with other parents of children with autism?" would not be a valid indicator of agency.

Another factor disregarded by the AQ is families' beliefs and approaches to autism. As reviewed earlier, there are different therapeutic approaches to autism that function well for different families. For instance, there may be some families that are strongly committed to the biomedical model and follow special diets and supplements. In

the AQ, no question pertains to such a practice. In a similar manner, people following the floortime model, would not tell the child in words how to play with toys (Question 18 from AQ); in the flooritme model the play partner would respect the child's choice of how to use a toy or any other object. Instead of teaching the "proper" manner, the adult would join the child and find an opportunity to increase shared attention and interaction through the interest of the child (Wieder & Greenspan, 2003).

Therefore, a limitation of the study is a questionnaire that may not be a valid indicator of agency considering the individuality of each child and family. This researcher was able to locate one other scale that measures involvement in parents of young children with autism; however, the scale was geared specifically towards behavior interventions (Solish & Perry, 2010). Another alternative would be to use a qualitative approach to study the topic; the problem then is that the variables could not be quantified and correlated.

Another limitation of the study is that the presence of the condition was not verified with a tool; it was only self-reported by the parents. Moreover, severity of the condition was not controlled. Regarding this, some have claimed that this variable affects parental involvement, when the condition is so severe parents may be drained and have little energy to be actively involved (Benson et al., 2008). Again, this issue is not acknowledged here when analyzing agency results. On the other hand, however, other researchers suggest differently, at least in regards to optimistic thinking. They argue that parental positivity may be relatively unaffected by behavior problems/symptomatology (Jones et al., 2013). Along these lines, another consideration worth mentioning is that the severity of the condition may determine how much a parent needs to do for the child;

therefore, this should be kept in mind when assessing agency.

Lastly, the format followed was strictly multiple choice. When an open ended question was given, it could have requested more detailed information regarding parental experiences on the topic being studied. Considering this, a mixed-methodology approach appears more suitable.

### **Implications**

One clear finding drawn from this investigation is that mothers of children with autism are highly more active in the development of the children than fathers. As discussed earlier, this disproportionate involvement may cause burden to fall on the mothers. For a clinician working with mothers, this would imply that they should be more sensitive to the role of the female and the unique experience she is having. In a similar manner, as per the discussion of positive psychology presented earlier, it would be ideal for professionals to implement interventions that not only would relieve the burden, but also increase the positive experience of the mother. Interventions with that purpose have been validated by Seligman et al. (2005); results of their study indicated that a simple exercise consisting of writing three good things that happened during the day, and explaining why they happened, would decrease depression, and increase happiness of the participants at one- two-, and six-month follow ups. Researchers suggest that a combination of exercises like the one just described with the coaching of a skilled professional would have even more lasting impact (Seligman et al., 2005).

Perhaps, this can be a practice easy to prescribe to mothers, so their negative symptoms would decrease and their happiness increase. It is important to warn, however, that the participants in the study by Seligman et al. (2005) were all interested in achieving

happiness. Individuals, who visited the positive psychology website of the authors, had access to a link to participate in the study. Perhaps, someone who is interested in positive psychology may not be equivalent to a person overcoming a crisis or suffering emotional burden. Hence, the effectiveness of such exercises within the population of parents of individuals in the spectrum needs to be investigated.

It could be argued that it is easy to keep a good mood and be positive when things are going well; however, the same may not apply in times of difficulties. Even with these concerns, positive emotions have been considered "active ingredients in superior coping and thriving despite adversity" (Fredrickson, Tugade, Waugh, & Larkin, 2003. p. 366). A prospective study of resilience and positive emotions after the terrorist attacks of 9/11 drew interesting results. In a sample of 47 college students, positive feelings, such as gratitude, love, and interest, after the attacks were critical to help resilient people thrive through the crisis. In other words, for individuals with a resilient trait, their positive emotions protected them from depression and helped them emerge from the crisis more satisfied with life, more optimistic, and more tranquil (Fredrickson et al., 2003).

Aligned with findings from Fredrickson et al. (2003), other researchers have concluded that a positive attitude toward caring for a child in the autism spectrum protects from experiencing the burden, while a negative attitude is strongly related to increased burden (Stuart & McGraw, 2009). Again, these results amplify the importance of promoting positive emotions among mothers of children with autism. Hence, although a relationship between dispositional optimism and agency was not established in this study, professionals in the field should be cognizant of the potential of optimism and other positive emotions, which can serve as protective factors in times of adversity.

#### **Conclusions and Recommendations for Future Research**

Research is an ongoing process that evolves as it progresses; every study opens the doors for other studies to take place, and investigators are responsible to make recommendations to keep the process going. Regarding the present study, although a relationship between optimism and agency was not established, it was shown that other variables such as age of the child and education of the parents also do not play a role in the active involvement in the development of the child. It is therefore still not clear if one specific internal trait would influence agency. Researchers then are called to explore in a lager sample whether or not optimism or another internal trait plays a role in agency.

Future research should consider the formulation of an agency scale that would not disregard the individuality of the family and the child. In addition, the effects of dispositional optimism in parenting behaviors should not be ignored. A future study in the topic should include a larger sample, a scale that addresses the issues discussed, and a mixed methodology so parents are given the opportunity to freely express themselves in regards to the topic.

Similarly, the role of optimism, as well as other positive emotions, should be better studied in this population. Some have already pointed towards the importance of optimism and other positive emotions (Baker et al., 2005; Ekas et al., 2010; Greenberg et al., 2004; Lloyd & Hastings, 2009; Stuart & McGraw, 2009; Warter, 2009). The presence of positive adaptation processes that would lead to resilience in parents of individuals in the autism spectrum has already been identified (Bayat, 2007). After interviewing 175 parents, emerging topics for some families included making positive meaning of the condition, becoming closer as a family, adopting greater appreciation of life, and even

gaining in spirituality (Bayat, 2007). The study of such topics has only begun, and results need to be transferred to educational and clinical settings.

Despite the limitations of the study, this investigation adds to the emerging body of literature on resiliency and positive topics in autism. Several messages were received from participants indicating pleasure in taking part of an optimism study, which points to the community's desire to move towards a positive approach. Enough has been said about depression, stress, financial crises, marital conflicts, and other negative topics related to parenting children with ASD. It is time now to analyze more in depth the effects of positive thinking, hope, optimism, resiliency, emotional intelligence, love, gratitude, forgiveness, laughter, and even spirituality, which could change the way we see the parenting special needs children.

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# Appendix A

Invitation to Participate in the Study

### Dear parent:

My name is Lina Maria Moyano, a Doctorate candidate in Special Education with a minor in Autism at Nova Southeastern University. Currently, I am working under the supervision of Dr. Judy Shoemaker on my dissertation research entitled: "The Role of Dispositional Optimism on Agency when Parenting a Child with Autism Spectrum Disorders". I am writing to you to invite you to participate in my online survey.

Considering the numerous challenges related to raising a child with autism, it can be difficult to remain optimistic and be proactive. Even so, optimism has been related to maternal well-being and family's quality of life among parents of children in the autism spectrum, and parental involvement is crucial for the development of the child. Expecting good things in life has not yet been analyzed as a possible predictor to the level a parent becomes proactive in the development of the child. My study aims to better understand that relationship.

If you are a parent of a child 18 years or younger diagnosed with Autism, Asperger's Syndrome, or Pervaseive Developmental Disorder- Not Otherwise Specified (PDD-NOS) you are eligible to participate. Both fathers and mothers are encouraged to participate. The survey can be conducted online and takes approximately 20 minutes to complete. Your answers will remain anonymous.

If you have questions about this study, I can be reached at <a href="mailto:lm1292@nova.edu">lm1292@nova.edu</a> or at 954-232-0507. Also if you would like to receive a copy of the results at the culmination of the study, feel free to contact me.

Please follow this link to enter the survey: <a href="https://www.surveymonkey.com/s/parentaloptimism">https://www.surveymonkey.com/s/parentaloptimism</a> I thank you for your participation!

Lina Maria Moyano, L.C.S.W. Nova Southeastern University <a href="mailto:lm1292@nova.edu">lm1292@nova.edu</a> 954-232-0507 Appendix B

Consent Form

### **Participation Letter**

Title of Study: The Role of Dispositional Optimism on Agency when Parenting a Child with Autism Spectrum Disorders

Principal investigator(s) Lina Maria Moyano, LCSW 3130 Commerce Parkway Miramar, Fl 33025 954-232-0507 Co-investigator(s) Judy Shoemaker, EdD c/o Applied Research Center Fischler School of Education 1750 NE 167th Street North Miami Beach, FL 33162 800-986-3223, Ext. 28500

Institutional Review Board Nova Southeastern University Office of Grants and Contracts (954) 262-5369/Toll Free: 866-499-0790 IRB@nsu.nova.edu

**Description of Study:** Lina Maria Moyano is a doctoral student at Nova Southeastern University engaged in research for the purpose of satisfying a requirement for a Doctor of Education degree. The main purpose of this study is to understand if there is a correlation between parental optimism and parental involvement.

If you agree to participate, you will be asked to complete the attached questionnaire. This questionnaire will help the writer identify if parents who have high levels of optimism are also more proactive in the development of the child. The questionnaire will take approximately fifteen to twenty minutes to complete.

**Risks/Benefits to the Participant:** There may be minimal risk involved in participating in this study. There are no direct benefits to for agreeing to be in this study except a possible a self-analysis of your optimism towards life and your behavior as a parent. Please understand that although you may not benefit directly from participation in this study, you have the opportunity to enhance knowledge as results from the study will inform future practices and treatment of children with autism that include parental involvement. If you have any concerns about the risks/benefits of participating in this study, you can contact the investigators and/or the university's human research oversight board (the Institutional Review Board or IRB) at the numbers listed above.

**Cost and Payments to the Participant:** There is no cost for participation in this study. Participation is completely voluntary and no payment will be provided.

**Confidentiality:** Information obtained in this study is strictly confidential unless disclosure is required by law. All data will be secured in a password protected file. Your name will not be collected.

**Participant's Right to Withdraw from the Study:** You have the right to refuse to participate in this study and the right to withdraw from the study at any time without penalty.

I have read this letter and I fully understand the contents of this document and voluntarily consent to participate. All of my questions concerning this research have been answered. If I have any questions in the future about this study they will be answered by the investigator listed above or his/her staff.

I understand that the completion of this questionnaire implies my consent to participate in this study.

Appendix C

Demographic Questionnaire

## Demographic Questionnaire (You)

1.	What is your gender? F M					
2.	How old are you?					
3. How do you best define yourself?						
	<ul> <li>a. White non-Hispanic</li> <li>b. African American</li> <li>c. Asian- American</li> <li>d. Hispanic or Latino</li> <li>e. Native-American</li> <li>f. Other</li> </ul>					
4.	What is your highest educational level completed?					
	<ul> <li>a. Middle School</li> <li>b. High- school</li> <li>c. Associate degree/ vocational/ professional certificate</li> <li>d. Some college</li> <li>e. Bachelor's Degree</li> <li>f. Master's / Doctoral degree</li> </ul>					
5.	What is your marital status?					
	<ul><li>a. Single</li><li>b. Married</li><li>c. Widowed</li><li>d. Divorced/ Separated</li><li>e. Domestic partnership</li></ul>					
6.	What is your approximate average household income?					
	<ul> <li>a. Under \$20,000</li> <li>b. \$20,000 - \$39,999</li> <li>c. \$40,000 - \$59,999</li> <li>d. \$60,000 - \$79,999</li> <li>e. \$80,000 - \$99,999</li> <li>f. \$100,000 - \$124,999</li> </ul>					
	g. \$125,000 - \$149,999					
	h. Over \$150,000					

- 7. How would you describe your current employment status?
  - a. Employed full time
  - b. Employed part time
  - c. Unemployed / Looking for work
  - d. Homemaker
  - e. Retired

## **Demographic questionnaire (your child)**

If you have more than one child with a diagnosis of an Autism Spectrum Disorder, please think about only one of them for the following questions.

- 8. Please specify the diagnosis of your child
  - a. Autism
  - b. Pervasive Developmental Disorder- Not otherwise specified (PDD-NOS)
  - c. Asperger's Syndrome
  - d. Not sure

9.	How	old is	your	child?	
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10. What is your child's gender? F M

Appendix D

Instruments

Life Orientation Test- Revised (LOT-R)<sup>1</sup> (Scheier et al., 1994)

#### **Instructions:**

Please answer the following questions about yourself by indicating the extent of your agreement. Be as honest as you can and try not to let your responses to one question influence your response to other questions. There are no right or wrong answers.

	Strongly	Disagre	Neutra	Agree	Strongly
	Disagree	e	1		Agree
1. In uncertain times, I usually expect the best	0	1	2	3	4
2. It's easy for me to relax	0	1	2	3	4
3. If something can go wrong for me, it will	0	1	2	3	4
4. I'm always optimistic about my future	0	1	2	3	4
5. I enjoy my friends a lot	0	1	2	3	4
6. It's important for me to keep busy	0	1	2	3	4
7. I hardly ever expect things to go my way	0	1	2	3	4
8. I don't get upset too easily	0	1	2	3	4
9. I rarely count on good things happening to me	0	1	2	3	4
10. Overall, I expect more good things happening to me than bad	0	1	2	3	4

<sup>&</sup>lt;sup>1</sup> From "Distinguishing Optimism from Neuroticism (and trait anxiety, self-mastery, and self-esteem): A Reevaluation of the Life Orientation Test," by M. F. Scheier, C. S. Carver, and M. W. Bridges, 1994, *Journal of Personality and Social Psychology*, 67(6), p. 1073.

## Agency Questionnaire<sup>2</sup>

Please circle the number that indicates how strongly you agree or disagree with the following statements.

How often do you . . .

	Never	Seldom	Sometimes	Often	Almost
					always
1. Learn new ways to encourage					
your child's language and					
cognitive development?					
2. Discipline your child?					
3. Choose or decide on an					
intervention strategy or					
treatment for your child?					
4. Educate your child?					
5. Teach your child social skills?					
6. Contribute to your child's					
quality of life?					
7. Serve as an advocate for your					
child to receive services?					
8. Learn new ways to manage					
your child's challenging					
behaviors?					
9. Provide feedback to your					
child's Early Intervention or					
school team about progress?					
10. Let professionals "who know					
best" (school officials,					
pediatricians, psychologists)					
decide on your child's					
education plan and medical					
intervention.					
11. Read books or articles on					
autism?					
12. Communicate with other					
parents of children with autism?					
13. Attend conferences or					
workshops on autism?					

<sup>2</sup> From "Maternal Self-efficacy and Associated Parenting Cognitions among Mothers of Children with Autism," by J. C. Kuhn and A. S. Carter, 2006, *American Journal of Orthopsychiatry*, 76(4), p. 553.

14. Make play dates with other			
children or seek out structured			
activities for your child to			
socialize?			
15. Follow your child's lead and			
focus of attention when playing			
with your child?			
16. Educate family members about			
autism?			
17. Show your child affection?			
18. Tell your child in words how to			
play with toys?			
19. Tell or show your child what to			
do in play to help them play at a			
more advanced developmental			
level?			
20. Imitate or copy your child's			
sounds, playful actions or play			
behaviors?			