AVOIDING CAREGIVER BURNOUT: A Comprehensive Workshop for Mothers of Children with Autism

A graduate project submitted in partial fulfillment of the requirements

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Marriage and Family Therapy

By

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“You’ve developed the strength of a draft horse while holding onto the delicacy of a daffodil ... you are the mother, advocate and protector of a child with a disability.”

~ Lori Borgman
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ABSTRACT

AVOIDING CAREGIVER BURNOUT: A Comprehensive Workshop for Mothers of Children with Autism

By

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Master of Science in Counseling,
Marriage and Family Therapy

Being able to cope with the strains and stresses of being a caregiver is part of the art of caregiving. In order to remain healthy so that individuals can continue to be caregivers, they must be able to see their own limitations and learn to care for themselves as well as others. This workshop is designed for mothers of children with autism who are experiencing signs of caregiver burnout, such as ongoing fatigue, depression, withdrawal from social contacts, change in eating habits, decrease in productivity, feelings of hopelessness and helplessness, stress, anxiety, and physical, mental, and emotional exhaustion. This is a one-day, eight hour workshop facilitated by a mental health professional specializing in working with children with autism and their families. The goal of the workshop is to help mothers recognize the physical, psychological, emotional, social, and financial stressors associated with caring for a special needs child. By identifying such stressors, parents are better able to implement positive and healthy ways of coping with the high demands of caring for a child with autism in hopes of avoiding caregiver burnout. The workshop will achieve its goal by providing participants with helpful resources, tips, information, support, and effective strategies which can help
minimize the burdens of caregiving and help maximize their own quality of life, ultimately improving their own caregiving skills.
Chapter One

Introduction

Autism; for parents of young children, this six letter word can conjure up an array of emotions, including fear, sadness, anger, guilt, hopelessness, despair, grief, and even shame. Accepting this diagnosis can be challenging for parents of children who have fallen victims to it; for autism does not only affect the child, but the entire family, both as individuals and as a whole. As a means of coping, many mothers have turned to the Internet and started blogging about their experiences and daily challenges they encounter raising an autistic child. The blogs offer support, tips, information, news, knowledge, and an outlet for parents and caregivers directly affected by this pervasive developmental disorder. Visitors of these websites are not only given the opportunity to gather vital information and read daily commentaries, but they themselves are able to share their stories, leave comments, and ask questions; in addition, parents and caregivers face little to no judgment by others, are provided with a sense of belonging and opportunity to bond, and are able to normalize the experiences and feelings they so often attributed to being exclusively unique to them.

The growing number of autistic cases, along with the Internet becoming more readily accessible over the past two decades, has resulted in the increase in parents turning to blogs as a means of coping with their child’s condition. The stories, feelings, and experiences shared by mothers of autistic children on these blogs have not only served as a therapeutic component to their overall health, but they have also brought awareness to a condition that physicians, psychologists, psychiatrists, therapists, and even the media so often correlate with the experiences of military combat soldiers, veterans,
and victims of assault: Post Traumatic Stress Disorder (PTSD). According to the National Institute of Health (NIMH, 2009), PTSD is an emotional illness that is classified as an anxiety disorder and usually develops as a result of a terribly frightening, life-threatening, or otherwise highly unsafe or stressful life experience(s). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV TR, 2000), the symptoms must be present for more than one month and include: flashback episodes, recurrent distressing memories of the event, repeated dreams of the event, physical reactions to situations that remind an individual of the traumatic event, feelings of detachment, inability to remember important aspects of the trauma, lack of interest in normal activities, less expression of moods, avoiding places, people, or objects that remind an individual of the event, sense of having no future, numbing of general responsiveness, difficulty concentrating, exaggerated response to things that startle (hyperarousal), excessive awareness (hypervigilance), irritability or outbursts of anger, sleeping difficulties, and impairment in social, occupational, or other important areas of functioning. On a specific Internet blog site, MOM – Not Otherwise Specified, which was created by a mother whose son was given the diagnosis of autism, Steiner, (2011) addresses the link between caregivers of children with autism and PTSD. The author not only states that the relationship between caregivers and PTSD is a growing issue that does not receive the attention it merits, but also shares her friends’ and her own symptoms, which closely mirror those outlined in the DSM-IV TR criteria for PTSD. On her blog, mothers reported experiencing physical reactions to loud noises, sleepless nights, ceaseless anxiety, sensory overload, agitation, and feelings of fear and helplessness. The blog further revealed that the source of the symptoms – the identified
“trauma” – varied from person to person. For some, it was the impact and subsequent upheaval of the diagnosis itself. For others, it was an event, or series of events, involving the autistic child’s aggressive behavior or indescribable fear; and yet for others, it was the toll exacted by constant vigilance, living life, day after day, in a metaphorical trench, watching and waiting for the next attack, but never being sure when it would come, how long it would last, and what kind of devastation it would leave behind (2011). Their daily struggles and symptoms were persistent and unmitigated; as a result, other areas of their lives were tainted.

Although not all parents of children with autism will meet the full criteria depicted in the DSM-IV TR, it is important to take into account the range of symptoms that do parallel those outlined for PTSD. These symptoms, if not addressed properly, can lead to more serious ramifications; thus, Post-Traumatic Stress Disorder symptomology should not be taken lightly. Symptoms that are not further explored and managed can lead to more serious side effects such as despair, depression, and in worst cases suicidal ideation and even death (Steiner, 2011). Because the risks of PTSD can potentially be life threatening, it is imperative that parents of children with autism address their symptoms before they escalate to a potentially fatal and more severe disorder such as PTSD, which can have detrimental effects on the psyche and be more difficult to treat. In an effort to avoid such complications, parents need to take preventative measures, such as recognizing and managing symptoms of Caregiver Burnout; a condition which can often precede PTSD. By doing so, parents and caregivers can better regulate their physical, emotional, and psychological health, which ultimately makes them better and more effective caregivers.
Statement of Need

Autism is a disorder of neural development characterized by impaired social interaction and communication, and by restricted and repetitive behavior. (American Psychiatric Association [DSM-IV], 2000). Currently, there is no known cure for autism; and in addition, not many children with the diagnosis live independently after reaching adulthood. As a result, parents may feel obligated and/or burdened with the lifelong responsibility of caring for their autistic child. These children exhibit prolonged dependency and require lifelong social and financial support. Schieve, Blumberg, Rice, Visser, and Boyle (2007) report increased psychological distress, including depression, anxiety, and components of stress such as decreased family cohesion and increased somatic complaints and burnout, among parents of children with autism in comparison to parents of typically developing children. The findings of this study suggest that the added pressures, responsibilities, and daily demands associated with caring for individuals with autism can often lead to caregiver burnout. Caregiver burnout is defined by researchers as a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude—from positive and caring to negative and unconcerned. Burnout can occur when caregivers do not receive the proper help or support they so desperately need, or if they try to do more than they are able. The strains and tensions of providing devoted care and attention day in and day out to a child with autism is also a significant contributing factor to caregiver burnout. Hence, it is important for all caretakers to make the effort to recognize the signs of burnout, and learn effective ways to positively cope with them. However, often the needs of the parents can be overshadowed by the demanding needs of those directly affected by autism; as a result, parents may place less
of a priority on their own health, which ultimately contributes to the deterioration in several domains of their life. Neglecting an individual’s needs can cause a breakdown in their personal life, their social life, their career, and their emotional, physical, psychological, and spiritual well-being. Furthermore, the increase in caregiver burnout and decrease in self-care can interfere with caretakers’ performance and ability to properly care for a child with a disability (2007). Thus, it is imperative that parents, mothers specifically, be given the proper knowledge to recognize the signs of caregiver burnout and have access to resources and information which can enable them to better cope with the everyday stress of caring for a child with autism.

**Purpose**

The purpose of this project is to create a psycho-educational workshop that meets the needs of mothers of children with autism where they are provided with the vital information and resources needed to appropriately recognize, acknowledge, assess, and cope with the stressors associated with caregiver burnout. During the workshop, the facilitator will work in partnership with the mothers to elicit information and knowledge on the topic at hand. By working collaboratively, participants may feel empowered, less isolated, and part of the process. The workshop may also serve the purpose to educate individuals working in the field of psychology, counseling, social work, therapy, and even medicine. With the growing number of children being diagnosed with autism in the United States, it is important for mental healthcare professionals and physicians to gain awareness on this increasing diagnosis and moreover, learn to recognize the signs of caregiver burnout as to better treat their clients and/or patients or refer them to more competent specialists in this field. It is important to note nonetheless, that the format of
the workshop would differ slightly for each audience (mothers at risk of burnout and practitioners in the field who need to recognize caregiver burnout), as the needs of those directly affected by burnout are different from practitioners. For the purpose of this project however, the focus will remain on mothers at-risk of burnout.

**Significance**

For years research on autism has focused on the individuals directly affected by this diagnosis. However, in more recent times, as will be described in the following chapter, researchers have dedicated much time and energy in documenting the effects of this disorder on family members, the family structure, and the family dynamics as well. This workshop will contribute to the ongoing research on the effects of autism on the family; more specifically it will address the daily challenges and stressors associated with caring for a child with autism from the mother’s perspective. The manifestation of these challenges can be seen in the overall deterioration of a mother’s physical, psychological, and emotional health and quality of life. Contributions on how families can effectively cope with caregiver burnout and the symptoms associated with it will be addressed. In addition, the workshop will not only benefit those mothers who are directly involved in the caring of their child, but it can also be adopted by clinicians, physicians, social workers, and institutions, thereby expanding the awareness and development of positive tools and skills for caregivers to better cope with their adverse circumstances. Trainees and interns in the field of psychology, counseling, and social work will also find the workshop to be valuable, as it will provide insight and information on how to better help potential clients who may be experiencing symptomology in correlation with caregiver burnout. Rao and Beidel (2009) indicate that interventions directed at either the child
and/or the parent would render ineffective if parenting stress limited treatment compliance. The researchers also assert that prior to implementing any form of intervention, it is important to assess the level of parental stress and family functioning and, if necessary, address those factors as a part of an overall treatment plan; otherwise, intervention efforts geared toward helping the autistic child may be attenuated by non- or partial compliance (2009). Therefore, it appears that reducing parental stress and improving psychological functioning, can ultimately increase the effectiveness of interventions designed to enhance child development, further adding to the validity and significance of the workshop.

Limitations

Although this workshop is designed to provide a comprehensive approach to introduce mothers to healthy coping mechanisms, it is impossible to include the breadth of information and knowledge that exists for caregivers into this brief one day workshop. Secondly, the targeted population for this workshop is mothers of autistic children, therefore, the needs of other caregivers, such as fathers and grandparents, may not be addressed. Although this may be a limitation of the workshop, feedback from the workshop can be used to develop other workshops in the future that are focused on a broader audience (i.e. fathers, grandparents, siblings, etc. of autistic children) who also face burnout. Additionally, this workshop offers information on numerous resources that can be utilized by parents to help alleviate some of the stresses and challenges experienced by caregivers, such as individual, group, and couples counseling; these resources, although proven to be beneficial, may be unavailable to some parents due to financial hardships. Obtaining such therapeutic help may cause additional stress in some
instances. Lastly, it is important to consider that every family with an autistic child is unique; therefore, each presents their own unique set of problems and challenges, and thus, it is impossible to address the needs of every parent in attendance.

**Terminology**

**Anxiety:** Fear or nervousness about what might happen (Merriam-Webster’s Learner’s Dictionary, 2003).

**Autism:** A disorder of neural development that appears in the first three years of life and affects the brain’s normal development of social and communication skills; it is also characterized by restricted and repetitive behavior (National Center for Biotechnology Information, 2012).

**Blog:** A website on which someone writes about personal opinions, activities, and experiences (Merriam-Webster’s Learner’s Dictionary, 2003).

**Caregiver:** An unpaid individual involved in assisting others (such as a child, an old person, or someone who is sick) with activities of daily living and/or medical tasks ([http://www.caregiver.org](http://www.caregiver.org)). *Throughout the paper, the words “caregiver” and “mother” are used interchangeably to mean the same thing.*

**Caregiver Burnout:** A state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude, from positive and caring to negative and unconcerned; burnout can occur when caregivers do not get the help they need, or if they try to do more than they are able ([http://webmd.com](http://webmd.com)).

**Coping:** To deal with problems and difficult situations and try to come up with solutions (Merriam-Webster’s Learner’s Dictionary, 2003).
**Depression:** A serious medical condition in which a person feels very sad, hopeless and unimportant and often is unable to live in a normal way (Merriam-Webster’s Learner’s Dictionary, 2003).

**Diagnosis:** The act of identifying a disease, illness, or problem by examining someone or something (Merriam-Webster’s Learner’s Dictionary, 2003).

**Disabled:** A physical or mental handicap, especially one that prevents a person from living a full, normal life or from holding a gainful job (http://dictionary.reference.com).

**DSM-IV TR:** The *Diagnostic and Statistical Manual of Mental Disorders*; published by the American Psychiatric Association and provides a common language and standard criteria for the classification of mental disorders (http://allpsych.com).

**Intervention:** Any measure whose purpose is to improve health or alter the course of disease (http://medical-dictionary.com).

**Quality of Life (QOL):** The degree of satisfaction an individual has regarding a particular style of life; standard indicators include physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity (National Institute of Health).

**Self-Care:** A key concept in health promotion, refers to decisions and actions that an individual can take to cope with a health problem or to improve his or her health (http://webmd.com).

**Special Needs Child:** A child that has a physical, mental, or emotional disability; the degree of disability can range from mild to severe (http://specialed.about.com).

**Stress:** A state of mental tension and worry caused by problems in your life, work, etc. (Merriam-Webster’s Learner’s Dictionary, 2003).
**Stressors:** Something that makes you worried or anxious; a source of stress (Merriam-Webster’s Learner’s Dictionary, 2003).

**Support:** To give help or assistance to (someone or something) (Merriam-Webster’s Learner’s Dictionary, 2003).

**Typically Developing Child:** A term used to describe a child who is not developmentally disabled and is able to process a great deal of nuanced social information that a developmentally disabled child cannot (http://specialed.about.com).

**Bridge**

Recognizing the signs of caregiver burnout may not always be easy, and knowing how to effectively cope with the stressors may be even more challenging. Through comparative studies, researchers have confirmed that parents of children with autism report higher levels of distress, depressive symptoms, anxiety, and emotional exhaustion, and lower levels of psychological well-being, adaptive coping skills, resources, and overall quality of life when compared to mothers parenting children with Down Syndrome, cerebral palsy, and typically developing children (Boyd, 2002; Estes et al., 2009; Lee et al., 2009; Rao & Beidel, 2009). Such findings imply that parents of children with the diagnosis of autism are at a higher risk for caregiver burnout since the stressors involved in caring for an autistic child appear to have greater consequences. Therefore, to better understand the effects of autism on parents and how they can better manage such challenges and stressors, it is important to revisit past research on this issue, which will be accomplished in the following chapter.
Chapter Two

Literature Review

Introduction

Historically, literature on families of children with autism has focused on the parents’ effects on the child; more recently however, the emphasis has shifted to an examination of the child’s effects on the parents, and mothers in particular. Research suggests that the presence of a child with autism presents a host of stressors to the family unit and caregivers. The following chapter explores the neural development disorder of autism and the effects it has on the family unit, including the parents, siblings, and marriage. Next, it shifts its focus from the family to primary caregivers, exclusively the mothers, and discusses the wide range of stressors that they experience as a direct result of caring for a child with autism. Finally, an analysis of the interventions and coping mechanisms utilized to manage the stressors experienced by caregiving parents is explored.

Autism

There has been a dramatic increase in the incidence of autism in the United States from the year 2000 to 2008; according to the Center for Disease Control (CDC, 2011), this incidence increased from one in 150 in the year 2000 to one in 88 in the year 2008. With more children than ever before being diagnosed with autism, it is unclear if this increase is due to changes in how pediatricians and psychologists identify and classify autism in people, or whether this is due to a true increase in occurrence. However, using the criteria outlined in the DSM-IV TR, Duarte, Bordin, Yazigi and Mooney (2005) assert that the autism spectrum disorders are the second most common serious
developmental disability after mental retardation/intellectual impairment, but are still less common than other conditions that affect children's development, such as speech and language impairments, learning disabilities, and ADHD. There is no lab test or X-ray that can confirm the diagnosis of autism; diagnosis of autism is based on clinical judgment regarding observations of the individual's behavior. According to Boyd (2002), information from family members and other observers is of primary importance in making the diagnosis; however, pediatricians may order tests to rule out other conditions that might be confused with autism, such as mental retardation, metabolic or genetic diseases, or deafness.

Autism is a condition surrounded by myth and generalizations about people with autism that are rarely appropriate. According to Duarte et al. (2005), the common beliefs that people with autism never express emotion, never smile or laugh, never make eye contact, never talk, and never display affection are simply myths. Just as every person is unique, with his or her own personality and characteristics, every person with autism manifests the disorder in his or her unique way. Lee et al. (2009) indicates that the list of symptoms and behaviors associated with autism is long, and each affected person expresses his or her own combination of these behaviors.

Autism is a complex developmental disability that usually is diagnosed early in childhood. Although the diagnosis of autism may not be made until a child reaches preschool or school age, the signs and symptoms of autism may be apparent by the time the child is aged 12-18 months, and the behavioral characteristics of autism are almost always evident by the time the child is aged 3 years (Lee et al., 2009; Rao & Beidel, 2009). Hoffman, Sweeney, Hodge, Wagner, and Looney (2009) found that children with
autism show signs of developmentally delayed social interaction and communication, and are often fascinated by repetitive activity. Numerous other studies have confirmed these findings, concluding that the mass majority of individuals with autism have problems using language, forming relationships, and appropriately interpreting and responding to the external world around them (Boyd, 2002; Duarte et al., 2005; Lee et al., 2009; Montes & Halterman, 2007). In addition, Marshall and Long (2010) found that both children and adults with autism have restricted ability to engage in and understand social interactions, and they often have trouble understanding other people’s feelings or interpreting their tone of voice and facial expressions. Consequently, the aforementioned studies have demonstrated that the effects of autism not only profoundly affect the life and capabilities of the child but of the entire family as well.

According to Brobst, Clopton and Hendrick (2009), individuals with autism have abnormal functioning in three core areas of development: social interaction, verbal and nonverbal communication, and the presence of repetitive and restricted patterns of behavior, interests, and activities. The diagnosis of autism is typically made when impairment is significant in all three areas. Duarte et al. (2005) delineate examples of the most common behaviors found to be exhibited by autistic children, as follows:

**Impaired reciprocal social interaction**

Examples include the following:

- poor use of body language and nonverbal communication, such as eye contact, facial expressions, and gestures;
- lack of awareness of feelings of others and the expression of emotions, such as pleasure (laughing) or distress (crying), for reasons not apparent to others;
• remaining aloof, preferring to be alone;
• difficulty interacting with other people and failure to make peer friendships;
• may not want to cuddle or be cuddled;
• lack of or abnormal social play;
• not responding to verbal cues (acting as if deaf).

**Impaired communication**

Examples include the following:

• delay in, or the total lack of, the development of spoken language or speech;
• if speech is developed, it is abnormal in content and quality;
• difficulty expressing needs and wants, verbally and/or nonverbally;
• repeating words or phrases back when spoken to (known as echolalia);
• inability to initiate or sustain conversation;
• absent or poorly developed imaginary play.

**Restricted repertoire of interests, behaviors, and activities**

Examples include the following:

• insisting on following routines and sameness, resisting change;
• ritualistic or compulsive behaviors;
• sustained odd play;
• repetitive body movements (hand flapping, rocking) and/or abnormal posture (toe walking);
• preoccupation with parts of objects or a fascination with repetitive movement (spinning wheels, turning on and off lights);

• narrow, restricted interests (dates/calendars, numbers, weather, movie credits).

**Behavioral symptoms include:**

• aggressive or self-injurious behavior;
• noticeable extreme under-activity or over-activity;
• throwing tantrums;
• short attention span;
• abnormal responses to sensory stimuli (for example, expressing over-sensitivity or under-sensitivity to pain);
• abnormalities in eating or sleeping;
• not responding to normal teaching methods;
• playing in odd or unusual ways;
• having inappropriate attachment to objects;
• having no apparent fear of dangerous situations (2005).

The cause of autism is unknown, and it is thought that the development of the condition is likely due to a number of factors rather than one single cause. Estes et al. (2009) has conducted a study on identical and non-identical twins which indicates that genetics play an important role in determining whether a child will be autistic. Boyd’s (2002) study on the cause of autism concludes that there is no single gene or genetic defect that is responsible for autism. According to Autism Speaks (2011), an autism
science and advocacy organization, there are a number of different genes that, when combined together, increase the risk of getting autism. Duarte et al. (2005) expanded their research to include other factors to play a role including digestive issues, dietary sensitivity or allergies, mercury poisoning and sensitivity to early childhood vaccination. However, findings from Schieve (2007), suggested that although the mercury preservative used in some vaccines is known to be neurotoxic, the most recent research on this subject does not propose a specific link between vaccines and autism.

Thus far, researchers have not been able to link one single gene or genetic defect that is responsible for autism. According to the CDC (2011), there are a number of different genes that, when combined together, increase the risk of getting autism. Duarte et al. (2005) found that in families with one child with autism, the risk of having another child with autism is three to eight percent and the concordance of autism in monozygotic twins is 30%. A number of studies, including one conducted by Brobst et al. (2009) have found that first-degree relatives of children with autism also have an increased risk of autism spectrum disorders. In some children, autism is linked to an underlying medical condition. According to Estes et al. (2009), examples include metabolic disorders (untreated phenylketonuria [PKU]), congenital infections (rubella, cytomegalovirus [CMV], toxoplasmosis), genetic disorders (fragile X syndrome, tuberous sclerosis), developmental brain abnormalities (microcephaly, macrocephaly, cerebral dysgenesis), and neurologic disorders acquired after birth (lead encephalopathy, bacterial meningitis). However, it is important to understand that these medical disorders alone do not cause autism as most children with these conditions do not have autism. In sum, many theories
as to what causes autism have been proposed, but none have been completely proven; what has been proven however, is the impact that autism has on the entire family.

**Autism and the Effects on the Family**

Children with autism face developmental challenges that can significantly affect parental and family functioning, creating stress for all members of the family. Rao and Beidel (2009) conducted a study in which 66% of parents reported that the parenting stress experienced as a result of caring for a special needs child affected family factors such as having little time for family activities, lack of spontaneity or flexibility, and stress surrounding the marital relationship. In another qualitative study, Marshall and Long (2010) identified several family life restrictions, including becoming socially reclusive rather than risk possible embarrassment from their child’s problem behavior, as revealed through the stories of five mothers parenting children with autism. In addition, Montes and Halterman (2007) also suggested that parents of children with autism reported higher levels of job-related stress, with fathers citing career restrictions and mothers reporting limitations on their ability to maintain employment or pursue outside activities; both spouses reported giving up other aspects of family life such as family outings and vacations. Similar studies comparing parents of children with autism to parents of typically developing children found that mothers of children with autism reported more family problems, significantly less family participation in recreational activities (due to the family spending extensive time engaged in activities surrounding the child’s restricted area of interest), and difficulties in family adaptability and cohesion (Boyd, 2002; Estes et al., 2009; Lee et al., 2009). In addition, families who experience difficulties in adaptability and cohesion have higher levels of depressive symptoms and anxiety (Rao &
Beidel, 2009). In sum, research has demonstrated that parents of children with autism have increased levels of stress and restricted family functioning compared to families with typically developing children. In most studies, parents identified child behavioral factors such as hyperactivity, demandingness, and disturbed mood as contributing to stress within the family system; thus, higher intellectual functioning does not appear to compensate for, nor ameliorate, the behavioral problems associated with ASD (Estes et al., 2009; Lee et al., 2009; Montes & Halterman, 2007; Rao & Beidel, 2009).

The literature investigating the impact of children with autism on siblings is mixed. Some studies have found positive effects for siblings of children with autism, such as increased positive self-concept, social competence, resiliency, and maturity (Brobst et al., 2009; Montes & Halterman, 2007). However, Lee et al. (2009) and Rao and Beidel (2009) revealed contrary findings, suggesting that siblings have increased levels of loneliness, depression, and more behavioral problems than siblings of children with no disorder. Boyd (2002) supports the latter, adding that siblings of children with autism may experience more social and behavioral adjustment problems and have less intimacy and nurturance than siblings in their control group. Overall, siblings had more behavior problems than a matched-aged control group; however, when data for sisters and brothers were analyzed separately, sisters had more positive self-concepts and sense of social competence than did brothers (Duarte et al., 2005). Competing for parent’s attention and time has also been found to increase friction between the typically developing child and their autistic sibling (Schieve et al., 2007). Schieve (2007) indicated that because mothers have to spend a majority of their time caring for their autistic child, they have less social contacts with family members, relatives, and community, ultimately
limiting the time they spend with their typically developing children. In an attempt to mitigate sibling and parent-child discord, parental support and communication are key (Boyd, 2002). Marshall and Long (2010) found that because siblings of children with autism are exposed to stressful life conditions, they may experience behavioral problems or “act out” in a subliminal effort to gain their parents’ attention. Furthermore, Marshall and Long (2010) indicate that siblings can become frustrated, angry, stressed and embarrassed by their brother or sister’s behavior at times; simultaneously, they may feel guilty and ashamed of these feelings. Siblings who were given permission to feel upset and to talk through their concerns and frustrations had an increased understanding of autism and showed signs of tolerance, responsibility, and maturity (2010).

The impact of parenting a child with autism on marriages has also been a focus of research. Studies by Duarte et al. (2005) and Rao and Beidel (2009) have found that having a child with autism places additional stress and economic pressures on the couple’s relationship, contributing to an overall increase in marital hardship and dissatisfaction. According to Schieve et al. (2007), couples already experience a variety of challenges that can jeopardize their relationships; however, when a child with special needs is thrown into the equation, the stress and strains of parenting can be intensified. They are often challenged with finding adequate time for both their children and their partners. Furthermore, the problems associated with raising an autistic child typically causes friction and tension between spouses; couples reported that the sadness, guilt and the depressive feelings often made it impossible to be happy and in some cases took the joy out of marriage. In other couples, the inability to express their sadness and pain further decreased their communication, ultimately creating a sense of isolation between
the two. Financial problems among families raising a child with autism are common, adding additional stress to the couple’s relationship. To pay for additional expenses to cover the costs of their child’s medical care and needs, fathers typically take on more hours at work, while mothers decrease work hours or stop working altogether to care for their special needs child; as a result, the couple often lacks the time and/or energy to spend quality time with one another (2007). In their study assessing the effects of autism on family functioning, Lee et al. (2009) found that divorce rates among couples parenting a child with autism were higher than for couples parenting typically developing children. According to Brobst et al. (2009), mothers whose children with autism had the most intense behavior problems reported lower levels of spousal support, respect for their partners, and commitment to their marriages. However, Montes and Halterman (2007) indicated that having a child with autism does not seem to increase the probability of the child living in a single parent home. Thus, further research on the relationship between caring for an autistic child and divorce is needed.

**Autism and the Effects on Primary Caregivers**

Parents caring for a child with autism experience a wide range of emotions and stressors; these stressors can often times be related to the child’s challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding (Hoffman et al., 2009; Schieve et al., 2007). A review of the literature demonstrates that research studies tend to focus on mothers of children with special needs as their sample in comparison to fathers. As noted by Hoffman et al. (2009), mothers generally take on the role of primary caregiver in families with children with developmental disabilities and thereby are the most adversely affected by the
negative impact associated with their child’s disability; hence they are most often the desirable target in research studies. The researchers suggesting negative emotional, social, physical and psychological impacts on the mother related to caring for their autistic child are numerous. Marshall and Long (2010) suggested that the parenting burden of caring for a child with autism falls more heavily on mothers than on fathers; as a result, mothers suffer the emotional consequences of that burden and experience depression and dysphoria at a higher rate than mothers of typically developing children. According to Montes and Halterman (2007), both mothers and fathers reported similar levels of stress related to the strains of caring for their special needs child; however mothers reported significantly higher levels of depression. Similar results were reported by Rao and Beidel (2009), who found that mothers parenting a child with autism were at a higher risk for not only depression, but anxiety and poor physical health as well. Chronic fatigue, high blood pressure, and heart disease were all reported to be high risk factors for caregiving mothers who neglected their physical wellbeing. Additionally, mothers of children with developmental disorders were also at a higher risk of using drugs and alcohol to cope with their situation in comparison to mothers of normally developing children (2009). To help mitigate these risks, higher levels of social support and emotional coping strategies were linked to better social adjustment, less severe depression and anxiety, and better physical health as reported by Hoffman et al. (2009). Hence, the research suggests that seeking help and emotional support seems to assist parents in better coping with the stressors associated with caring for a child with autism.

According to multiple researchers, few disorders in children pose a greater threat to the psychosocial well-being of parents than autism (Marshall & Long, 2010; Schieve et
Stressors for these caregivers include: the autistic child’s disruptive, antisocial behavior, parents’ difficulties obtaining diagnosis and treatment, the public’s ignorance of and insensitivity to the public behavior of autistic children, the autistic child’s language and cognitive deficits, the nature of intensive treatment programs for autism, and difficulties communicating with professionals involved in the child’s care (Borbst et al., 2009; Estes et al., 2009). A number of studies described in this chapter confirm that parents of children with autism report higher levels of stress, depression, anxiety, and emotional exhaustion than parents of children with Down syndrome or other types of mental retardation (Borbst et al., 2009; Estes et al., 2009; Hoffman et al., 2009; Schieve et al., 2007). Furthermore, several large surveys reported similar findings, including increased psychological distress, such as depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic complaints and burnout, among mothers of children with autism and related autism spectrum disorders in comparison to mothers of typically developing children (Estes et al., 2009; Lee et al., 2009; Marshall & Long, 2010). In a study sampling twenty parents of children with autism, Brobst et al. (2009) found that these parents reported more parental stress and greater trouble with child behavior problems; they also reported somewhat lower total social support and relationship satisfaction than did parents in the comparison group. However, while many of the aforementioned studies suggest that child problem behavior is associated with elevations in parenting stress and psychological distress in mothers, Boyd (2002) and Duarte et al. (2005) have found limited evidence of a relationship between the severity of children’s autism and parental stress.
Using the *Parenting Stress Index*, a study by Hoffman et al. (2009) found that mothers of children with autism reported higher levels of stress than mothers of typically developing children on 13 of 14 subscales; the levels of stress reported by mothers in the autism group were extremely high, at the 99th percentile. Estes et al. (2009) indicated that self-injury was the strongest predictor of maternal stress in a sample of 51 children with autism. Moreover, these researchers also reported that impaired adaptive functioning may increase parental stress; parents of children with lower daily living skills may face increased child-rearing responsibilities. Estes et al. also found that when greater assistance is needed to accomplish daily tasks such as dressing, bathing, and toileting, parents experience an increase in stress or psychological distress (2009). Lee et al. (2009) conducted a study in which the parents were also shown to display elevated levels of stress. They surveyed 89 parents of children with autism and 46 parents of children without disabilities; comparisons between the two groups indicated that parents of children with autism reported significantly higher levels of stress and significantly lower levels of adaptive coping and resources; these results suggested that the presence of a child with autism contributed to the lower overall quality of life (QOL) for this group of parents. In addition, the researchers also found a connection between family income, number of children, and physical health. Higher income was associated with better physical health, providing parents with access to more resources. Moreover, having more children in the family predicted a higher level of parent-reported physical health as well, suggesting that the presence of siblings may allow for some shared caretaking responsibilities (2009). In addition, studies have also found disruption in sleeping patterns (sleep quality is poorer and sleep quantity is lower), increased fatigue, decrease
in social adjustment and psychological functioning, isolation, and feelings of guilt and fear to be apparent in mothers caring for a child with autism (Duarte et al., 2005; Estes et al., 2009; Rao & Beidel, 2009).

**Coping Mechanisms**

Yes, it is true that caring for an autistic child can cause an increase in daily stress and a breakdown in family cohesion; however, caring for a special needs child does not sentence a caregiver to a lifelong road of distress, pressure, and worry. Studies have shown that parents who accept their situation and learn how to positively cope with it, are better equipped to live healthier and fulfilled lives.

Several studies have emphasized the importance of outside support groups for parents of disabled children; Lee et al. (2009) indicated that parents who attend support groups do so in an effort to meet other people in their situation and share their feelings. The primary motivator behind attending these groups was the mere need for support; parents reported feeling abandoned both by society and their own families, creating a feeling of isolation and even depression (2009). According to Yalom (2005), parents who attend such support groups are provided with a sense of universality; by sharing common experiences and feelings, participants become less isolated, more validated, and are given the opportunity to create bonds with other parents. Moreover, parents of disabled children understand that they are not alone in their struggles. Montes & Halteman (2007) also reported on the benefits of attending support groups, providing parents with an outlet to share their experiences, receive feedback and support, and provide empathy. However, being heard and feeling validated provided parents with the most comfort (2007). According to Duarte et al. (2005), attending support groups served as the number one
coping mechanism among a sample of mothers caring for their autistic child; attending such group meetings on a consistent basis helped caregivers build relationships with other families in similar situations and gave parents something to look forward to. Additionally, support groups provided mothers with a therapeutic arena to share feelings and gain empathetic support. Furthermore, researchers Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) suggest that parents of disabled children who have strong family and social support report more positive affect; higher levels of support were also found to correspond to fewer spousal problems and an internal locus of control corresponded to lower levels of depression and isolation.

In a 2010 study conducted by Marshall & Long, mothers reported that religion served as their coping mechanism, providing them with the understanding, patience, and strength needed to care for their autistic child. Daily prayers and attending religious services, (either at churches or temples) helped mothers accept their child’s condition and helped lessen their negative feelings of guilt, resentment, and anger over their child’s developmental disability. Attending religious services also served as a place of social support, providing the women with faith and social interactions with others outside of their immediate families, helping lift the veil of social isolation (2010).

Engaging in quality relaxation time ranked at the top of the list in overall coping mechanisms for many mothers. Several researchers reported that breaking away from their daily caregiving responsibilities and routine and participating in a pleasurable activity either once a day or once a week, dramatically decreased the amount of stress mothers caring for their autistic children experienced (Boyd, 2002; Lee et al., 2009; Marshall & Long, 2010). Montes & Halterman (2007) and Rao & Beidel (2009) indicated
that meditation, including yoga and slow breathing techniques, aided parents in reaching a state of calmness and for some, even helped boost their energy. Estes et al. (2009) stressed the importance of partaking in self-care activities; because taking care of an autistic child is extremely time consuming and stressful, the needs of the parents are often neglected. As a result, mothers in the study became depressed, anxiety-ridden, experienced trouble sleeping, lost or gained weight, and felt physically and emotionally exhausted. To help alleviate some of their symptoms, mothers were encouraged to set time aside for themselves; during this time, research participants engaged in relaxing activities, including going for a walk, taking a bath, getting a massage, doing yoga, reading, and exercising. Mothers who engaged in such activities reported feeling less depressed and more attuned with their caregiving responsibilities (2009). According to Duarte et al. (2005), exercise played a key role in helping mothers of autistic children regain a sense of control and feel less physically exhausted. Research participants felt anger over their child’s developmental disability, their child’s condition was out of their control, and even more upsetting, there was no cure. Their lives would now be devoted to taking care of their special needs child; as a means of coping, mothers found refuge in exercising. Exercising not only had its physical advantages, but it also provided these caregiving mothers with a sense of control (control over their own bodies) and a stress outlet. In addition to exercising, meditation and outside support also held top spots in helping caregivers cope with their situation.

Additionally, providing parents with short-term child-care services can offer them temporary relief of their caregiving responsibilities and allow them to enjoy other activities. A study conducted by Abelson (1999), indicated that there is a high demand for
affordable and accessible respite care, especially during the summer months when most public schools are out on break. It has been noted that respite care has a positive effect on the family functioning and coping. Respite care provides the parents with the opportunity to take a break, therefore reducing the incidence of caregiver burnout and fatigue, as well as providing parents with more time for their non-disabled children and leisure activities (1999).

Thus, as outlined in the literature, the health risks associated with caring for a child with autism run high; furthermore, ignoring the signs of stress and overload can have detrimental effects on parents’ physical, emotional, and psychological well-being. A decrease in social interactions and/or activities and a breakdown in the family unit have also been seen to affect the lives of parents caring for their autistic children. With such findings documented in past research, caregivers are urged to take part in self-care rituals in an effort to avoid caregiver burnout.
Chapter Three

Method of Project

Overview

The foundation of the workshop will embrace a psycho-educational component or approach; however, it will also tap into coping strategies which will include forming or joining support groups, relaxation techniques, and self-care. The topic of focus will be caregiver burnout, specifically targeting mothers of children with autism. Vital information will be given regarding recognizing the signs and symptoms of caregiver burnout, assessing the severity of the signs and symptoms, distinguishing the difference between physical, emotional, social, and psychological symptoms, and finding methods to appropriately and effectively cope with each of them. In addition, risk factors, stressors, and the sometimes unsettling negative feelings associated with caring for a child with a developmental disorder will also be discussed and shared among the mothers in attendance. Consequences stemming from not treating or managing caregiver burnout will furthermore be addressed. In a study addressing the impact of children with autism on parental stress, sibling adjustment, and family functioning, Rao and Beidel (2009) discovered that the developmental challenges associated with autism create significant stress for all family members and a breakdown in family functioning. In response to such findings, the workshop will also address the effects of autism on the entire family, including the impact on the siblings, the father, and the marriage. Relationships within the nuclear family are not the only factors jeopardized when raising a child with autism, however. Research indicates that the stressors involved in parenting a child with autism significantly contribute to the overall decline in self-care, spirituality, and quality of life,
and can moreover cause an increase in job-related stress and financial burden (Hoffman, Sweeney, Hodge, Wagner, & Looney, 2009; Marshall & Long, 2010). The implication that stressors can adversely affect other domains of a mother’s life is a cause for great concern and will therefore furthermore be addressed in the workshop.

Coping strategies will be the topic of focus during the second half of the workshop. Parents will be provided with tips, techniques, information, and resources geared to help them better manage burnout. A list of local therapists, which serve as individual, family, or group counselors specializing in the area of autism will be provided to all individuals in attendance; organizations catering to the needs of developmentally disabled children and their families will also be included in the list. Joining support groups and the idea of blogging will also be introduced. In addition, the names of books and websites which promote encouragement, inspiration, support, and insightful information on the related topic of caring for an autistic child will also be accessible to participants. Moreover, mothers will participate in small group activities; the goal of the activities is to encourage dialogue and create a sense of universality amongst the participants. During this time, participants will have the opportunity to not only share experiences and meet with one another, but exchange contact information as well. It is important that mothers reach out to other families with autistic children as a means of support; hence, exchanging information with other mothers in attendance can ultimately serve as a coping mechanism. Furthermore, a short segment on meditation will also be implemented in the workshop as a means of coping with the daily stressors experienced by mothers. By practicing meditation techniques, individuals can achieve improved well-being and personal healing on a spiritual and physical level. In short, meditation has the
potential to assist parents of children with autism in achieving a more fulfilling life regardless of their external circumstances. At the closing of the workshop, participants will be guided through a relaxation technique; the activity will aid in reducing stress by helping to attain a state of increased calmness; or otherwise reduce levels of anxiety, stress or anger. According to Rao and Beidel (2009), relaxation techniques are often employed as one element of a wider stress management program and can decrease muscle tension, lower blood pressure and slow heart and breath rates, among other health benefits. In sum, the workshop is aimed at providing a holistic approach in the identification, assessment, and treatment of caregiver burnout, paying particular attention and awareness to the sensitive needs of vulnerable mothers parenting children with autism. To best address these needs, the workshop will take on a collaborative approach, meaning the facilitator will present vital information in a lecture style presentation and information will be elicited from mothers themselves to make them feel empowered and part of the process. It is the hope that by attending this workshop, participants will increase their capacity to be effective caregivers while maintaining a healthy lifestyle.

**Target Population**

This workshop is intended for mothers of autistic children. Mothers are the targeted population because they tend to take on the primary responsibilities for childcare in families with children with developmental disabilities. Although the majority of primary caregivers can potentially benefit from the workshop, only the unique experiences, feelings, and challenges faced by mothers will be addressed. Mothers of all ethnic and cultural backgrounds, socio-economic statuses, age, and sexual orientation, are welcome to attend.
Recruitment

Participants for this workshop will be recruited using three methods: email, distribution of flyers, and referrals. Emails notifying potential participants of the nature of the workshop, including its purpose and goals will be sent out to mothers of autistic children. Email addresses will be obtained from various sources that are lawfully allowed to disclose such personal information, including (but not limited to) doctors’ offices, autism specialists, schools, and treatment facilities, all of which either treat children with autism or offer their families services. Professional flyers will also be distributed at these same facilities where parents of children with autism often frequent. The flyers will include a description of the workshop, workshop logistics, pricing, date and time of workshop, location, registration information, and a phone number to contact if interested. Flyers will be posted on bulletin boards and left in waiting rooms for parents to read and take home. In addition, referrals by therapists, doctors, specialists, and teachers will also be welcomed. The goal is to recruit anywhere from twenty to fifty mothers to attend the workshop; groups larger than fifty are discouraged, as they may present limitations surrounding small group activities and discussions.

Qualifications of Facilitator

The facilitator of the workshop must be any of the following: a licensed counselor, a licensed marriage and family therapist or social worker (interns with at least two years experience working with families of autistic children eligible), psychologist, or an individual holding a special education degree. It is vital that the facilitator have significant knowledge and experience working with developmentally disabled children and their families. It is equally important that leaders of the workshop conduct
themselves in a professional and respectful manner; being courteous, helpful, and responding to the needs of attendees is essential. The facilitator must feel comfortable and confident speaking in front of a large audience and keep his/her audience engaged throughout the duration of the workshop. Facilitators must also work collaboratively with the mothers in attendance to help make the workshop a success. Moreover, it is necessary that workshop facilitators maintain awareness of appropriate cultural considerations. Professionals need to strive to be sensitive to cultural and individual differences, including those due to age, gender, race, ethnicity, national origin, religion/spirituality, sexual orientation, ability level/disability, and socioeconomic status. Additionally, since the workshop addresses the topic of meditation, it is highly preferred (but not required) for the facilitator to have knowledge of meditation techniques. Potential facilitators will not have to attend a training session to administer the workshop; he/she will reference the PowerPoint presentation and Facilitator Manual that I have put together to carry out the workshop. Any question, concerns, and/or comments can be addressed with me before the commencement of the workshop.

**Space**

The workshop should be held in a large classroom setting, however, an amphitheater setting is preferred for groups larger than thirty-five. All attendees should have full view of the material being shown and should be able to fully understand the facilitator. The room should have enough seating for everyone, with the facilitator conducting the workshop front and center. It is preferred that a podium be placed next to the facilitator, however it is not required. Additionally, the facilitator must have ample room to walk around, keeping his/her audience engaged. Adjustable lighting is preferred.
and a restroom should be conveniently located outside the room. Any special accommodations should be addressed and implemented before the start of the workshop.

**Materials**

The facilitator will require the following materials for the workshop: a white board, dry erase markers, an eraser, a laptop, a projector, a large screen, a chair, and a microphone headset; a podium for the presenter is also preferred, but not required. The facilitator will provide the following materials to each individual in attendance: handouts, a copy of the PowerPoint presentation, a business card, and a journal for each participant to take home. Bottled water will also be available for those in attendance. Internet access is also required.

**Funding**

Funding for the workshop will come from the registration fees paid by participants. Money from the fees will be used to pay for the following: the workshop facilitator, journals, copies of handouts and PowerPoint presentation, bottled water, and rental of space.

**Registration**

Individuals interested in attending the workshop will be given two options to register. Those interested can log-in to a secure Internet website where they will be asked to input their name, billing information, credit card number (including expiration date and three-digit security code), and how they heard about the workshop. The second option will be to call a toll free number; here, individuals will be asked to enter their credit card information and answer how they heard about the workshop; to do so, individuals will be given automative answers and will choose the option that best corresponds to their
answer by using their dial keypad. A confirmation number will be provided to each individual who registers. Participants will be asked to bring this number with them to the workshop as they will need it upon checking in. All major credit cards will be accepted, including, Visa, MasterCard, American Express, and Discover.

**PowerPoint**

The workshop will be presented utilizing a PowerPoint presentation. The presentation will consist of forty-three PowerPoint slides. The facilitator will begin the workshop by introducing him/herself and allowing participants to introduce themselves as well. After, the facilitator will present an overview of the workshop and address the question, “Why Are We Here?” Challenging behaviors displayed by the autistic child and feelings associated with having an autistic child will follow. The effects that autism has on the family as a whole, siblings, the marriage, fathers, mothers, and careers, will also be presented. Before the conclusion of the first half of the workshop, participants will break up into small groups and share their personal accounts on how autism has impacted their lives. A forty-five minute lunch break will proceed. At the start of the second half of the workshop, individuals will participate in a self-care inventory exercise. Following the activity, the facilitator will wrap up the presentation by reviewing the following: caregiver burnout, (including its symptoms, stages and causes), distinguishing the difference between stress and caregiver burnout, tips to prevent caregiver burnout and coping mechanisms. Small group discussions on coping strategies will also take place. The workshop will end with a poem written by a mother about her autistic child and a journaling exercise; followed by the completion of the evaluation form and coming to a close with a relaxation technique known as guided imagery (See Appendix A).
Facilitator Manual

A manual outlining each PowerPoint slide will be available for facilitators of the workshop. The manual will contain additional information that is not presented in the actual PowerPoint slide presentation; facilitators can utilize this information during the workshop to elaborate on the topic at hand. Additionally, the manual will include a description of each of the activities that will take place during the workshop, as well as a description on each of the handouts that will be distributed to the mothers in attendance (See Appendix A).
Chapter Four

Summary

Becoming a parent is an exciting and often times stressful journey for mothers and fathers; the needs and safety of their children become of primary concern, as their own needs become secondary. Raising a child to become an independent productive citizen is the goal of many parents alike; however, when a child is diagnosed with autism, the dreams and aspirations many parents share for their children shatter. Their child is now considered “different,” and will be forever stigmatized by being labeled autistic. For many with this diagnosis, living independently is a milestone they will never reach. Learning basic functions such as communicating with others, regulating and expressing emotions, impulse control, and appropriately socializing with peers are all challenges both child and parent face together. Typically, it is the mothers in the family that take on the primary caregiving responsibilities for their special needs child; consequently, they spend a myriad amount of time, energy, and money trying to help their child cope with their disorder as best as possible. However, many mothers become so involved and overwhelmed with their child’s caregiving needs that they easily forget about their own well-being, ultimately neglecting their physical, emotional, and psychological health. In order to remain healthy so that mothers can keep up with their autistic child’s caregiving demands, they must learn to recognize their own limitations and take care of themselves as well as others. In an effort to do so, mothers must learn to recognize the signs and symptoms of caregiver burnout. Feeling burnt out can be physically and emotionally draining, avoiding signs of burnout can result in feelings of depression, loneliness, fatigue, anger, anxiety, frustration, and guilt. Moreover, mothers who neglect their own
well-being also experience negative consequences in other domains of their lives, including but not limited to their marriage, relationships with their typically developing children, friendships, and career. Because the consequences of caregiver burnout run extremely high, it is of the upmost importance that caregivers of developmentally disabled children educate themselves on avoiding such a condition and learn effective coping mechanisms that can improve both their own health as well as the quality of caregiving received by their children. Thus, attending a workshop which caters to the overall health needs of mothers of children with autism is essential.
References


Appendix A

PowerPoint Slides

AVOIDING CAREGIVER BURNOUT: A COMPREHENSIVE WORKSHOP FOR MOTHERS OF CHILDREN WITH AUTISM
<table>
<thead>
<tr>
<th>INTRODUCTIONS</th>
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<td><strong>GROUP FACILITATOR:</strong></td>
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<td>❖ Credentials</td>
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<td>❖ Goal of Workshop</td>
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<td><strong>GROUP PARTICIPANTS:</strong></td>
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<td>❖ Expectations</td>
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<td>❖ Questions</td>
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<td>OVERVIEW</td>
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<td>Why are we here?</td>
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<td>Challenging</td>
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<td>autistic child</td>
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<td>Feelings associated with having a developmentally disabled child</td>
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<td>Autism &amp; the effects on the Family</td>
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<td>Autism &amp; the effects on Mothers</td>
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<td>What is Caregiver Burnout?</td>
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<td>Avoiding Caregiver Burnout</td>
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<td>Coping Mechanisms</td>
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<td>Accessing Resources</td>
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<td>Relaxation Technique</td>
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WHY ARE WE HERE?

- 2 in 3 caregivers have health problems (many due to stress or self neglect).
- 2 in 3 caregivers experience strains on their marriages and families.
- Half of caregivers are financially strained by the caregiving cost and/or the loss of income.
- More than ¼ of caregivers feel despair.
- Research demonstrates that mothers typically take on primary caregiving responsibilities for their developmentally disabled children.
- Research has shown that mothers caring for their child with autism typically suffer from physical, emotional, psychological, social, spiritual, and/or financial stress.

Source: Family Caregiving Alliance
The workshop will address the specific needs of mothers who are primary caregivers to their child with autism.

Mothers will be provided with the tools necessary to better manage their stressors and improve their overall health and well-being.

Mothers will learn to recognize the signs of Caregiver Burnout and learn effective coping mechanisms.

Attending the workshop is a step towards a healthier lifestyle and improved quality of life.
<table>
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<tr>
<th>CHALLENGING BEHAVIORS DISPLAYED BY AUTISTIC CHILD</th>
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<tr>
<td>▪ Aggressive &amp;/or self-injurious behaviors</td>
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<td>▪ Compulsive behaviors</td>
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<td>▪ Deficits in social skills</td>
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<td>▪ Disruption in sleep patterns</td>
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<td>▪ Temper tantrums</td>
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<td>▪ Short attention span</td>
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<td>▪ Lack of spontaneity</td>
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<td>▪ Delayed communication skills</td>
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<td>▪ Lack of emotional regulation &amp;/or expression</td>
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<td>▪ Lack of appropriate social play</td>
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<td>▪ No apparent fear of dangerous situations</td>
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*Source: Autism Research Institute*
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<th>Feelings</th>
<th>Source: <a href="http://www.autism-help.org">www.autism-help.org</a></th>
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<td>Sadness/Loss</td>
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<td>Anger</td>
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<td>Grief</td>
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<td>Fear (of the future)</td>
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<tr>
<td>Denial</td>
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**Remember that ALL of these feelings are 100% NORMAL**
CAN YOU RELATE?
<table>
<thead>
<tr>
<th>AUTISM &amp; THE EFFECTS ON THE FAMILY</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Less family cohesion and adaptability</td>
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<tr>
<td>- Life restrictions/social reclusiveness</td>
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<tr>
<td>- Lack of spontaneity or flexibility</td>
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<tr>
<td>- Limited time for family activities, vacations, and/or recreation</td>
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<tr>
<td>- Increase in stress (for all family members)</td>
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<tr>
<td>- Increase in family problems</td>
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<tr>
<td>- Restricted family functioning</td>
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<tr>
<td>- Less time spent as a family</td>
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<tr>
<td>- Isolation from friends, relatives, and community</td>
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<tr>
<td>- Embarrassment from child’s problem behavior</td>
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<tr>
<td>- Negative reactions or lack of tolerance from society</td>
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<td>- Financial strains</td>
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<table>
<thead>
<tr>
<th>AUTISM &amp; THE EFFECTS ON SIBLINGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Embarrassment around peers</td>
</tr>
<tr>
<td>- Jealousy and/or resentment regardiing amount of time parents spend with their brother/sister</td>
</tr>
<tr>
<td>- Competing for parents’ attention</td>
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<tr>
<td>- “Acting-out” as a means of gaining parental attention</td>
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<tr>
<td>- Frustration over not being able to engage, communicate, or play with their brother/sister</td>
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<tr>
<td>- Being the target of aggressive behaviors</td>
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<tr>
<td>- Feelings of resentment, animosity, and/or anger towards brother/sister</td>
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<tr>
<td>- Concern over their role in future caregiving</td>
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</table>
## AUTISM & THE EFFECTS ON SIBLINGS

- Trying to make up for the deficits of their brother/sister
- Concern regarding their parents’ stress and grief
- Social and behavioral adjustment problems
- Feelings of loneliness and depression
- Feelings of isolation
- Less intimacy and nurturance
- Feeling neglected

*Source: Lee et al. (2009); Rao and Beidel (2009) and Marshall and Long (2010)*
Some studies have found positive effects for siblings of children with autism, such as:

- Increased positive self-concept
- Social competence
- Maturity
- Increase in resiliency
- Increased tolerance & understanding of individuals with developmental disorders

Source: Brobst et al. (2009) and Montes and Halterman, (2007)
RESOURCES FOR SIBLINGS

- The ARC of the U.S. offers The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members; seeking to increase peer support and information opportunities for brothers and sisters of people with special needs and to increase parents’ understanding of sibling issues. [www.thearc.org](http://www.thearc.org)

- Autism New Jersey, Inc. matches siblings with pen pals around the country as well as internationally.


- Sibling Information Network can be reached at (203) 486-4034.
RESOURCES FOR SIBLINGS

- **NASP (National Association of Sibling Programs) Newsletter**. Published by the Sibling Support Project, Children’s Hospital and Medical Center, PO Box 5371, CL-09, Seattle, WA 98105-0371.

- **The Sibling Information Network Newsletter**. Published by the A.J. Pappanikou Center, University of Connecticut, 1776 Ellington Road, South Windsor, CT 06074.

- Individual counseling

- Support groups

**A reference sheet will be handed out at the closing of the workshop with additional resources for siblings and parents**
<table>
<thead>
<tr>
<th>AUTISM &amp; THE EFFECTS ON MARRIAGE</th>
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<tbody>
<tr>
<td>▪ Added stress</td>
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<tr>
<td>▪ Economic pressures</td>
</tr>
<tr>
<td>▪ Financial hardships</td>
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<tr>
<td>▪ Increase in marital dissatisfaction</td>
</tr>
<tr>
<td>▪ Limited (or no) time for each other</td>
</tr>
<tr>
<td>▪ Lower levels of spousal support</td>
</tr>
<tr>
<td>▪ Feeling neglected</td>
</tr>
<tr>
<td>▪ Decrease in displays of affection</td>
</tr>
<tr>
<td>▪ Less commitment to the marriage</td>
</tr>
<tr>
<td>▪ Increase in arguing &amp; tension</td>
</tr>
<tr>
<td>▪ Less sharing of caregiving responsibilities between spouses, creating feelings of anger &amp; resentment</td>
</tr>
<tr>
<td>▪ Increase in separations &amp; divorce</td>
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</tbody>
</table>

Source: Duarte et al. (2005) and Rao and Beidel (2009)
Forced to work longer hours at work
- Increased financial pressures
- Less marital satisfaction
- Preoccupied with worries about their spouse’s emotional well-being
- Decline in time spent with their spouse
- Feeling ignored or forgotten by their spouse
- Decline in sexual contact with wives
- Decline in their partner’s libido
- Lack of communication with partner
- Feeling of isolated

Source: Schieve et al. (2007) and Brobst et al. (2009)
To pay for additional expenses to cover the costs of their child’s medical care and needs, fathers *typically* take on more hours at work, while mothers decrease work hours or stop working altogether to care for their special needs child. Studies have also suggested that parents of children with disabilities experience an increase in job-related stress; often times, they are forced to leave work early and take multiple days off, negatively impacting their overall work performance. Consequently, they may be overlooked when being considered for promotions and bonuses. Although discrimination during the hiring process is illegal, employers may feel reluctant to hire an individual who has a special needs child.

*Source: Hoffman et al. (2009)*

“*How many of you have had similar experiences?*”
Mothers who take on the role of primary caregivers to their child with autism and are offered little to no support and neglect their overall health are at a high risk for the following:

- Social isolation
- Alienation
- Fatigue
- Physical exhaustion
- Emotional exhaustion
- Depression
- Lack of sleep
- Poor diet
- Elevated stress
- Anxiety
- Poor physical health
AUTISM & THE EFFECTS ON MOTHERS

- High blood pressure
- Diabetes
- High cholesterol
- Heart disease
- Increase use of alcohol, drugs, and/or other drugs
- Feelings of guilt, anger, frustration, grief, hopelessness, & helplessness
- Feeling overwhelmed and/or irritable
- Lack of social support
- Lack of spousal support
- Financial problems/worries
- Relationship dissatisfaction
- Poor relationships with non-disabled children
### AUTISM & THE EFFECTS ON MOTHERS

- Pressure to “do it all”
- Feelings of inadequacy
- Life put “on-hold”
- Lack of resources
- Limited contact with friends and family
- Lack of self-care
- Sacrifices in personal and career goals
- No time or energy for leisure activities
- Worry/fear about child’s future
- Chronic sorrow
- Maladaptive coping mechanisms
- Caregiver burnout


“Can you think of any others?”
SMALL GROUP ACTIVITY:

“HOW HAS RAISING A CHILD WITH AUTISM DIRECTLY AFFECTED YOU & YOUR FAMILY?”
ACTIVITY: SELF-CARE INVENTORY
Essentially, caregiver burnout a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude -- from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able -- either physically or financially. Caregivers who are "burned out" may experience fatigue, stress, anxiety, and depression. Many caregivers also feel guilty if they spend time on themselves rather than on their ill, disabled, or elderly loved ones.

The symptoms of caregiver burnout are similar to the symptoms of stress and depression. They include:

- Withdrawal from friends and family/avoidance of social activities
- Loss of interest in activities previously enjoyed
- Feeling blue, irritable, hopeless, and helpless
- Changes in appetite, weight, or both
- Changes in sleep patterns
- Feeling physically run down/getting sick more often
- Feelings of wanting to hurt yourself or the person for whom you are caring
- Loss of energy and constant feeling of emotional and physical exhaustion
- Excessive use of alcohol and/or sleep medications
## SYMPTOMS OF CAREGIVER BURNOUT

- Ongoing fatigue
- Difficulty concentrating
- Loss of interest in your appearance and grooming
- Feeling increasingly angry, resentful, bitter, or blaming yourself or others
- Engaging in nervous habits such as binging, chain smoking, and/or drinking
- Feeling increased stress and anxiety over minor things
- Despairingly blaming yourself for your inability to meet unrealistic demands
- Feeling everything is out of control, with no way out

THE 3 STAGES

STAGE ONE – **FRUSTRATION:**
The primary caregiver expresses continuing frustration and disappointment over the care recipient’s deteriorating condition or lack of progress.

STAGE TWO – **ISOLATION:**
The primary caregiver struggles to maintain a sense of purpose in working so hard to provide care. He or she may express feelings of loneliness, being unappreciated, second-guessed or criticized by other family members and the care recipient.

STAGE THREE – **DESPAIR:**
The primary caregiver feels helpless and adrift. The primary caregiver is unable to concentrate and loses effectiveness as a caregiver. He or she is no longer excited about the progress or response of the care recipient to quality care.

*Source: ALS Association*
### COMMON CAUSES OF CAREGIVER BURNOUT

- Role Confusion
- Unrealistic Expectations
- Unreasonable Demands
- Lack of Control

- Personality Traits
- Never-Ending Tasks
- Multiple Roles
- Self-Sacrifice
- Unspoken Feelings

THE "THREE R" APPROACH

1. RECOGNIZE: Watch for the warning signs of burnout.
2. REVERSE: Undo the damage by managing stress and seeking support.
3. RESILIENCE: Build your resilience to stress by taking care of your physical and emotional health

Source: www.helpguide.org
# STRESS VS. BURNOUT

<table>
<thead>
<tr>
<th>STRESS</th>
<th>BURNOUT</th>
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<tbody>
<tr>
<td>1. Characterized by over-engagement</td>
<td>1. Characterized by disengagement</td>
</tr>
<tr>
<td>2. Emotions are over-reactive</td>
<td>2. Emotions are blunted</td>
</tr>
<tr>
<td>4. Loss of energy</td>
<td>4. Loss of motivation, ideals, &amp; hope</td>
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<tr>
<td>5. Leads to anxiety disorders</td>
<td>5. Leads to detachment &amp; depression</td>
</tr>
<tr>
<td>6. Primary damage is physical</td>
<td>6. Primary damage is emotional</td>
</tr>
<tr>
<td>7. May kill you prematurely</td>
<td>7. May make life seem not worth living</td>
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</table>

Source: [www.helpguide.org](http://www.helpguide.org)
TIPS TO PREVENT CAREGIVER BURNOUT

- Confide your feelings in someone you trust.
- Set realistic goals (know your limitations).
- Accept help when someone offers it to you.
- Be realistic about your loved one’s disease/disorder.
- Don’t forget about yourself because you are too busy taking care of someone else.
- Talk to a professional.
- Take advantage of respite care services.
- Set boundaries and do a reality check of your personal situation.
- Recognize and accept your potential for caregiver burnout.
- Educate yourself.
- Develop new tools for coping.
- Adopt healthy eating, sleeping, and exercising habits.
- Accept your feelings.

Source: http://women.webmd.com/caregiver-burnout
DISCUSSION:
“How do you cope with raising a child with autism?”
**COPING MECHANISMS**

- Attending support groups
- Blogging
- Religion/prayer
- Meditation (i.e. yoga, breathing exercises, guided imagery, nature walks)
- Exercising
- Journaling
- “Me Time” (i.e. massage, bath, sleeping, reading, mani/pedi, listening to music, watching t.v. etc.)
- Spending time with friends & family
### COPING MECHANISMS

- Attending therapy (individual, family, couples, or group)
- Getting a babysitter
- Seeking a case manager
- Reaching out to other mothers of autistic children
- Advocacy
- Respite care

“A SPECIAL DROP OF LOVE”
A POEM BY A MOTHER OF AN AUTISTIC CHILD
"A Special Drop of Love"

A special drop of love was deposited in my womb with care
The unconditional love you give to me is so very rare
When you were born, Oh! What a glorious day!

I never knew there could be a love so strong
I am so blessed, because in my heart there is a song
A song of peace and assurance
A song of strength and endurance
When I look into your eyes, my heart feels your love
A Special Drop of Love came from heaven above

Your smile gives your face that special glow
Whenever you look at me, my love for you continues to grow
The Hugs! The Kisses!
These are moments of pure gold
They are treasures I have hidden deep within my soul
Many told me you would not make it this far
But look at you now, gleaming like a shining star
Every sound you make is like music to my ears
The look you give me helps wipe away my tears
Many have wondered, "Why me?"
I looked at you and wondered, "Don't they see what I see?"
Many have wondered, "What am I going to do?"
But when I look at you, I know I can make it through
Yes, I get tired sometimes and the tears begin to flow
But then you reach for my hand and that's when I know
That healing comes after the pain
And the sun comes after the rain

God trusted me with such a treasure
The joy I feel is beyond measure
As each day turns into night
I feel the strength to continue to fight
As each night turns into day I know that God hears every prayer I pray
My hopes and my dreams are far beyond me
Your encouragement and joy allows me to be free

A Special Drop of Love came from above
A precious little package for me to LOVE
I know I am strong and can conquer any trial
When I look in your face and see your smile

Written by Bishop Helen E. London
QUESTIONS?
PLEASE TAKE A FEW MINUTES TO COMPLETE THE EVALUATION FORM. FORMS MAY BE KEPT ANONYMOUS.

THANK YOU FOR YOUR ATTENDANCE & PARTICIPATION!

PLEASE REMAIN SEATED ONCE YOU HAVE COMPLETED YOUR EVALUATION; WE WILL END THE WORKSHOP WITH A RELAXATION EXERCISE.
ACTIVITY: 
A GUIDED IMAGERY EXPERIENCE
THANK YOU!
Appendix B

Facilitator Manual

Slide #1: Workshop Title
Avoiding Caregiver Burnout: A Comprehensive Workshop for Mothers of Children with Autism

Slide #2: Introductions
Facilitator will introduce him/herself to the workshop participants; during this time he/she will discuss his/her credentials, the experience he/she has with working with children with autism and their families, and the goals of the workshop. These goals include: providing vital information and resources needed to appropriately recognize, acknowledge, assess, and cope with the stressors associated with caregiver burnout and providing a safe platform for mothers to share their experiences, educate other mothers, and gain support.

Slide #3: Overview
The facilitator will briefly outline the topics that will be discussed during the course of the workshop. The activities which the mothers will be participating in may also be mentioned at this time; these activities include: forming small groups and answering the question, “How has raising a child with autism directly affected you and your family?” completing a self-care inventory exercise, discussing as a group the different ways in which mothers have coped with their situation, completing a journaling exercise, and lastly, participating in a relaxation technique.

Slides #4-5: Why Are We Here?
The facilitator will explain the various reasons why this workshop is not only important, but necessary for the health and well-being of mothers who take on the role of primary caregiver to their child with autism. After presenting the statistics on slide #4, the facilitator will remind the participants that the realization of these statistics is not true for all caregivers; however those that do not take care of their own needs do become at high risk of becoming a statistic themselves. Slide #5 explains the benefits of the workshop.

Slide #6: Challenging Behaviors Displayed by Autistic Children
Although children diagnosed with autism display a wide variety of behaviors, the behaviors listed on slide #6 are those that have been identified by mothers as being the most challenging and stressful. After listing the behaviors presented on slide #6, the facilitator may ask the participants the following question, “Which behaviors displayed by your child have caused you the most amount of stress?” Participants may answer the question by raising their hand and sharing their experiences with the group.

Slides #7-8: Feelings Associated with Having an Autistic Child
Slide #7 lists some of the negative feelings parents may experience due to having a child with autism. Mothers are to be reminded that they should not feel ashamed or guilty about their feelings, but should instead share their feelings with a trusted individual.
Keeping such feelings to oneself can be unhealthy and can have physical and emotional consequences. It is also important to remind mothers that experiencing such negative feelings is normal and more common than they may think. Slide #8 displays images of the many different emotions that mothers may be experiencing. The caption reads, “Can you relate?” At this time, mothers can be given the opportunity to share some of their own feelings with the group.

**Slide #9: Autism and the Effects on the Family**
Slide #9 lists some of the negative effects raising a child with autism has on the entire family unit, according to documented research. The facilitator may want to elaborate on this topic; indicating that because so much time, energy, and money is spent on the autistic child, other members of the family begin to feel neglected. Moreover, the child’s unpredictable and sometimes problematic behavior makes it difficult for the family to participate in social/recreational activities and spend time together; as a result, the family unit may weaken and problems may begin to arise. Additionally, family members may become isolated from their friends, community, and extended family; parents may find it easier to stay at home (where their child’s behavior is kept private) rather than risk embarrassment and/or rude remarks from society. The financial burden of medical costs and therapy for the autistic child adds additional stress to the family.

**Slides #10-12: Autism and the Effects on Siblings**
Slides 10-11 lists the various negative effects that autism has on siblings; it is important to remember that the “normally” developing children in the family may experience negative feelings and/or experiences directly related to their brother/sister’s disorder. The facilitator may want to remind the mothers in attendance that many of their children suffer in silence over their brother/sister’s condition; while others “act-out” as a desperate plea to gain parental attention. Because parents focus the majority of their time and energy on their autistic child, many siblings feel that they must compete for their parents’ (especially their mother’s) attention, creating feelings of jealousy, animosity, and resentment toward their autistic sibling. As a result, siblings may begin to feel neglected, isolated, and depressed. Some siblings may become concerned over their parents’ increased stress and their well-being; additionally, they may become concerned over their role in their brother/sister’s future caregiving. It is important that the facilitator encourage mothers to talk to their non-autistic children often and allow them to speak about their feelings and concerns. These siblings need love and attention as well; perhaps mothers can commit to spending one-on-one time every week with their non-autistic child to help the two bond. It is important that siblings feel validated and important, especially in a world where autism takes center stage. Slide #12 discusses some of the positive effects on siblings that researchers have found. Studies have indicated that some siblings experience an increase in resiliency (the ability to overcome challenges), maturity, tolerance of people in the world (accepting others who are different), social competence (the skills necessary to be accepted and fulfilled socially), and positive self-concept (how we perceive ourselves to be).

**Slides #13-14: Resources for Siblings**
A small list of organizations and newsletters that cater to the needs of siblings are listed on slides #13-14; a reference sheet with additional resources will be handed out to mothers at the end of the workshop.

**Slide #15: Autism and the Effects on Marriage**
Having an autistic child can take a toll on the marriage; usually one parent (the mother) spends more time caring for their autistic child than the other; as a result, the other parent begins to feel neglected by his/her spouse. Feeling neglected can create a host of marital problems, including infidelity, lack of support, marital dissatisfaction, decrease in affection, increase in arguing and tension, and divorce. Since one partner feels neglected by the other, they become less committed to the relationship and the two may begin to drift apart. It is important for the facilitator to express to his/her audience that not all marriages will encounter such problems or otherwise end in divorce; however, having an autistic child can create added stress to a marriage. Couples counseling is encouraged.

**Slide #16: Autism and the Effect on Fathers**
In several studies, fathers have reported negative feelings and experiences surrounding their marriage, sex life, and finances. Since mothers typically take on the role of primary caregiver to their autistic child, the father typically takes on the role of primary breadwinner. As a result, they experience financial pressures from family. Consequently, they are forced to spend longer hours at work and less time at home, further expanding the gap between husband and wife. Once home, either wife or husband (or both) are too tired to engage in any type of sexual activities. As a result, husbands can begin to feel neglected and ignored, thus reporting more marital dissatisfaction.

**Slide #17: Autism and the Effects on Career**
Slide #17 describes in detail the negative effects that having an autistic child can have on both the mother’s career and the father’s career. The facilitator is to read the slide aloud and ask participants, “How many of you have had similar experiences?” This will give mothers the opportunity to share their career experiences with the entire group.

**Slides #18-20: Autism and the Effects on Mothers**
Slides #18-20 provide a detailed list of the possible negative effects that caring for an autistic child can have on a mother’s physical, emotional, psychological, and social health. Since the mothers in attendance are the primary caregivers to their autistic child, they often experience the most negative effects and the most severe ones as well. It is important that the facilitator read each negative effect listed on the slides; the length of the list is not intended to scare the mothers, but instead to bring awareness to the health risks associated to neglecting one’s own well-being. At the end of the list, the facilitator is to ask the audience if they are able to come up with any additional health hazards. It is important that the facilitator remind the mothers in attendance that not every caregiver will experience such negative effects, however neglecting their own needs does put them at a higher risk of becoming ill.

**Slide #21: Small Group Activity**
During this time the facilitator will break the participants up into small groups. The size of the groups will depend on how many individuals actually attend the workshop. Groups of four to eight are most desirable. It is important that the facilitator does not assign too many people to one single group, as this can create feelings of isolation within the group and may not allot enough time for everyone in the group to participate. Once the facilitator has assigned everyone to a group, the individuals will sit with their assigned group members and introduce themselves. The group will then answer the following question, “How has raising a child with autism directly affected you and your family?” The groups will have fifteen-twenty minutes to answer the question and discuss it amongst their group. Once the time is up, the facilitator will ask if any members of the group would like to share their response. Participants are not forced to share, only those who feel comfortable enough to share will do so. The purpose of the activity is to encourage mothers to open up about their own experiences and provide support to other mothers in attendance.

Slide #22: Break!
Forty-five minutes will be given to the group to eat lunch and use the restroom. Participants are asked to please return to their seats after forty-five minutes.

Slide #23: Activity – Self-Care Inventory
Upon returning from lunch, participants will engage in a twenty-five question self-care and lifestyle balance inventory. The inventory will examine the individual’s physical, psychological, and spiritual efforts at maintaining a balanced lifestyle. By answering each question and assigning a corresponding numerical response, participants will be able to assess their lifestyle and determine whether or not they are balancing their caregiving responsibilities with their overall health needs. If participants have proven to be managing their health poorly, a plan of action can be implemented to improve self-care skills. Participants will be given ten-fifteen minutes to complete the inventory. Once the inventory has been completed, participants will be asked to raise their hands as their corresponding score is called. This will give both the facilitator and the group an idea of how people scored. Discussion of the activity will follow.

Slide #24: What is Caregiver Burnout?
Slide #24 provides a definition of caregiver burnout according to webmd.com.

Slides #25-26: Symptoms of Caregiver Burnout
The following two slides include a list of all possible symptoms of caregiver burnout. The facilitator is to read each symptom aloud; at the end of the list, the facilitator may ask the mothers if they have experienced any of the symptoms listed and if so, which ones.

Slide #27: The 3 Stages
Slide #27 outlines the three stages of caregiver burnout; stage one (Frustration) occurs when the caregiver becomes frustrated over the care recipient’s deteriorating condition or lack of progress. The primary caregiver has difficulty accepting that the quality of care and effort put forth has nothing to do with the actual health-related decline or mood of the care recipient. For mothers of autistic children, their child’s lack of progress or
developmental regression may cause them to feel frustrated and disappointed at their own caregiving skills. In **stage two** (Isolation), the primary caregiver struggles to maintain a sense of purpose in working so hard to provide care. He or she may express feelings of loneliness, being unappreciated, second-guessed or criticized by other family members and the care recipient. Reality of the care recipient’s condition and the limitations of caregiving are not accepted. The primary caregiver is reluctant, unable or unwilling to reach out for help from others. Mothers in this stage may feel like they are alone; they are unaware of their limits as caregivers and believe they can do it all on their own. Asking for help is not an option. During the **third stage** (Despair), the primary caregiver feels helpless and adrift. The primary caregiver is unable to concentrate and loses effectiveness as a caregiver. He or she is no longer excited about the progress or response of the care recipient to quality care. As a consequence, the primary caregiver neglects personal care and well-being, loses interest in the community, social contact and respite activities, such as reading books, watching movies or other stimulating activities. At this point, the feeling of being “burnt-out” kicks in; mothers of autistic children may begin to neglect their personal, physical, and emotional needs. Some may even become depressed; at this point, intervention is critical for both the caregiving mother and the vulnerable child.

**Slide #28: Common Causes of Caregiver Burnout**

On slide #28, nine possible causes of caregiver burnout are listed. The facilitator is to read each cause aloud and elaborate on each one. 1.) **Role Confusion:** Many people are confused when thrust into the role of caregiver. It can be difficult for a person to separate her role as caregiver from her role as spouse, lover, child, friend, etc. 2.) **Unrealistic Expectations:** Many caregivers expect their involvement to have a positive effect on the health and happiness of the patient. This may be unrealistic for patients suffering from a progressive disease, such as Parkinson's or Alzheimer's. 3.) **Unreasonable Demands:** Some caregivers place unreasonable burdens upon themselves, in part because they see providing care as their exclusive responsibility. 4.) **Lack of Control:** Many caregivers become frustrated by a lack of money, resources, and skills to effectively plan, manage, and organize their loved one's care. 5.) **Personality Traits:** Many caregivers have perfectionistic tendencies (nothing is ever good enough); a perfectionist continually focuses on what needs to be improved, rather than what has been accomplished. When this becomes their focus, they may never feel that they have succeeded at anything. 6.) **Never-Ending Tasks:** Never-ending tasks describe work that appears to lack both a beginning and end. This can lead caregivers to feel as if they have no closure, and therefore have not completed anything. 7.) **Multiple Roles:** Many caregivers play a number of important roles, such as wife/husband, mother/father, caregiver and breadwinner. It is easy to feel overwhelmed when they are trying to play multiple roles. 8.) **Self-Sacrifice:** Self-sacrifice occurs when caregivers agree to take on certain tasks despite their true desire to complete them. When they continually agree to things that they would rather not do, they inevitably become resentful. 9.) **Unspoken Feelings:** Any emotion that is unexpressed creates “blocks” in a caregiver’s ability to complete tasks and to function in relationships. If they do not speak about how they are truly feeling in a situation, those emotions surface in other, unproductive ways such as being chronically late, frequently forgetting things, or reacting in ways that are inappropriate to the situation.
Slide #29: The Three “R” Approach
By implementing the three “R” approach, mothers can deal with burnout more effectively. Recognizing the warning signs of burnout, Reversing the damage by managing stress and seeking support, and building Resilience to stress by taking care of your physical and emotional health is a quick and easy way for mothers to stay healthy.

Slide #30: Stress vs. Burnout
Slide #30 examines the ways in which stress and burnout differ from one another. Because feeling burnt-out evolves from feeling stressed, it is important that mothers are able to distinguish the difference between the two, as untreated burnout can have detrimental consequences.

Slide #31: Tips to Prevent Caregiver Burnout
Since the theme surrounding the workshop is avoiding caregiver burnout, it is important that the facilitator provide a tip reference for participants to re-visit once the workshop has ended. Once the facilitator has read each of the thirteen tips aloud, he/she may ask the group the following questions, “How many of you already implement at least one of these tips to your life?” “How many of you will reference this list the next time you’re feeling overwhelmed or burnt-out?” The facilitator must reinforce the importance of maintaining good overall health and the importance of taking time to nurture one’s soul. Caregiver burnout is a serious matter and can be prevented; however it is up to the mothers to give priority to their own needs. Putting the health needs of others before their own does not necessarily make them better caregivers, in the long run, it can make them ineffective caregivers to our children.

Slide #32: Discussion
During this time, the facilitator will ask the question, “How do you cope with raising a child with autism?” The question will be addressed to the entire group; participants will be free to answer the question by raising their hand and waiting for the facilitator to call on them. At this time, mothers will get the opportunity to share some of their own coping mechanisms, while listening to other coping strategies shared by the mothers in attendance.

Slides #33-34: Coping Mechanisms
Slides #33-34 lists a variety of coping mechanisms for the mothers of the workshop. These coping mechanisms are designed to help caregivers alleviate stress, improve their overall health, and avoid caregiver burnout. These coping mechanisms include, attending support groups; by doing so, mothers are able to share their experiences and feelings in a safe environment all while gaining the support from other individuals in their same situation. Taking to the internet and blogging about their struggles and experiences as a mother of an autistic child has become a way in which individuals can still receive the support they so desperately need, all while remaining in the comfort of your own home.
Religion and meditation are also introduced to the group as coping mechanisms; some families have found that praying and/or attending religious services has helped them cope with the reality of their situation and has instilled hope in their lives. Meditation (i.e. yoga, relaxation techniques, etc.) is also a great way to relax the mind, body, and soul, regain energy, clear your head, and reach a state of calmness. Additionally, exercising has been proven to help relieve stress, energize, and help maintain physical health. Writing down your thoughts and feelings in a journal can also be therapeutic for individuals experiencing daily struggles. Moreover, one of the best ways to de-stress is to engage in some personal quiet time; during this time individuals may take a bath, get a massage, take a nap, or go for a walk. Stepping away from your daily routine of caring for others and doing something for yourself can give an individual something to look forward to and can keep them from getting burnt-out. Furthermore, spending time with family and friends and seeking the support from other families experiencing similar situations as your own can help expand your support network. For many individuals, seeking professional help in a therapeutic setting (i.e. individual, family, couples, or group therapy) can help them feel empowered, validated, and supported. Lastly, it is suggested that mothers reach out to a social worker who can help them access local resources for themselves and their special needs child.

Slides #35-37: “A Special Drop of Love”

A poem written by a mother of an autistic child will be read by the facilitator. The purpose of the poem is to promote inspiration and instill a sense of universality among the mothers in attendance. The poem may also encourage participants to utilize writing as a coping mechanism and as an emotional outlet. The purpose of the poem is also to provide inspiration for the next activity, journaling.

Slide #38: Activity – Journaling

During this next activity, the facilitator will pass out journals to each participant; the facilitator will explain that the journals are for them to keep and write in as often as they’d like. The facilitator will go on to explain that journaling can serve a therapeutic purpose; jotting down your feelings and challenges can promote the examination of everyday experience as offered through everyday language, this is known as self-reflection and has been widely used in therapeutic settings. The facilitator will ask that everyone complete their first journal entry by writing down anything that comes to mind, whether it be a poem, a story, their feelings, etc. Participants will have ten-fifteen minutes to complete the exercise.

Slide #39: Questions

At this time, the facilitator will be available to answer any questions the mothers may have.

Slide #40: Evaluation
At the closing of the workshop, participants will be asked to fill out an evaluation form. The purpose of the evaluation is to provide feedback on the overall performance of the presenter and whether or not the workshop met the expectations of the participants. Evaluations will be kept completely anonymous and the input provided will be considered for future workshops.

**Slides #41-42: Activity – A Guided Imagery Experience**

At the end of the workshop, participants will be guided through a relaxation technique called, guided imagery. As the lights are dimmed, participants will be asked to close their eyes, relax and focus on the facilitator’s voice as he/she guides them towards a state of calmness and inner peace. As the facilitator reads the meditation script, participants will engage in slow and deep breathing techniques, and then asked to release all tension in their bodies, muscles, and joints. Once physical relaxation has been achieved, the facilitator will begin to guide the participants through a journey of deep inner stillness. On this journey, participants will envision themselves on a white sandy beach and will use their sense of smell, touch, vision, and hearing to imagine their physical presence on this journey. The goal of the exercise is to transport the individual to a place where he/she is able to step away from the stresses of their reality and step into a haven of safety, tranquility, peace, and relaxation. Guided imagery can help individuals de-stress and is a healthy form of meditation. Participants will be encouraged to implement meditation exercises to help relieve stress and cope with their external circumstances.

**Slide #43: Thank You!**

Facilitator thanks his/her audience for their participation in the workshop. The facilitator will let the participants know that he/she will stay in the classroom once the workshop is over to answer any additional questions or address any comments the mothers may have.
Facilitator Manual

Handouts/Activities: Description and Purpose

Self-Care Inventory

This is a twenty-five question self-care and lifestyle balance inventory. The inventory will examine the participant’s physical, psychological, and spiritual efforts at maintaining a balanced lifestyle. By answering each question and assigning a corresponding numerical response, participants will be able to assess their lifestyle and determine whether or not they are balancing their caregiving responsibilities with their overall health needs. If participants have proven to be managing their health poorly, a plan of action can be implemented to improve self-care skills. Once participants have completed the inventory, they will get the opportunity to share their feelings and concerns with the group.

Guided Imagery Exercise

Participants will be guided through a relaxation technique called, guided imagery. As the lights are dimmed, participants will be asked to close their eyes, relax and focus on the facilitator’s voice as he/she guides them towards a state of calmness and inner peace. As the facilitator reads the meditation script, participants will engage in slow and deep breathing techniques, and then asked to release all tension in their bodies, muscles, and joints. Once physical relaxation has been achieved, the facilitator will begin to guide the participants through a journey of deep inner stillness. On this journey, participants will envision themselves on a white sandy beach and will use their sense of smell, touch, vision, and hearing to imagine their physical presence on this journey. The goal of the exercise is to transport the individual to a place where he/she is able to step away from
the stresses of their reality and step into a haven of safety, tranquility, peace, and relaxation. Guided imagery can help individuals de-stress and is a healthy form of meditation. Participants will be encouraged to implement meditation exercises to help relieve stress and cope with their external circumstances.

**Poems**

A collection of seven poems written by mothers of children with autism will be handed out to attendees during the workshop. The poems express the many feelings, challenges, and experiences endured by mothers whose children are considered to be “special.” The purpose of the poems is to promote inspiration and instill a sense of universality among the mothers in attendance. The poems may also encourage participants to utilize writing as a coping mechanism and an emotional outlet. Hence, the benefits of journaling and using self-reflection as a therapeutic intervention will be introduced.

**Benefits of Meditation**

Meditation is a great way for people to de-stress and improve the quality of their lives. It requires no special equipment, and is not complicated to learn. It can be practiced anywhere, at any given moment, and it is not time consuming; best of all, it is completely free. Because the health benefits of meditation are numerous, the workshop includes it as a coping mechanism for mothers who are under an immense amount of stress caring for their developmentally disabled child. To better inform mothers on the advantages of meditating, a hand-out entitled, *100 Benefits of Meditation*, will be given to participants to take home. The hand-out includes the physiological, psychological, and spiritual
benefits to meditating and is used to both promote and encourage stressed out mothers to adopt meditation as a means to help relieve stress and improve their health.

**Stress Diagram**

A handout entitled, *The Effects of Stress*, will be given to participants. The handout provides guests with a visual image of the negative consequences chronic stress may have on an individual’s physical, mental, and emotional well-being. Participants may use the handout as a reference to help them understand and recognize the negative effects that untreated stress may have on them. Participants are encouraged to discuss any stress-induced illness with their physician or a mental health professional.

**Tips for Caregivers**

Participants of the workshop will also be provided with a handout on family caregiving tips. The handout outlines ways in which caregivers can attend to their emotional, social/recreational, and physical needs. The handout provides tips on how to maintain overall health and well-being by taking some time for oneself. By referencing the handout when feeling overwhelmed with their caregiving responsibilities and implementing the tips, mothers may be able to relieve some of the stress and pressures they may be experiencing as primary caregivers to their autistic child.

**Evaluation**

At the closing of the workshop, participants will be asked to fill out an evaluation form. The purpose of the evaluation is to provide feedback on the overall performance of the presenter and whether or not the workshop met the expectations of the participants. Evaluations will be kept completely anonymous and the input provided will be considered for future workshops.
Appendix B

Self-care and lifestyle balance inventory

Source: Headington Institute

Please note that this scale is not a clinical diagnostic instrument and is provided for educational purposes. It merely examines some of the more effective physical, psychological and spiritual methods of staying balanced and preventing burnout. If you have any concerns about your state of emotional health, you should consult with a mental health professional.

Instructions: In the last month, how often has the following been true for you? For each question, write the number that best fits your experience on the line before the question.

1. I have at least one full day off work each week.
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

2. I take some time for myself to be quiet, think, meditate, write and/or pray.
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily

3. I work for less than ten hours a day.
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily

4. I do aerobic exercise (walking, running, swimming etc) for at least 25 minutes at a time.
   (0) Never / (1) Seldom / (2) Once a week / (3) Twice a week / (4) 3 or more times/week

5. I do something I find fun (e.g., play a game, go to a movie, read a book etc).
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily

6. I practice muscle relaxation, pilates, yoga, stretching, meditation or slow-breathing techniques.
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily

7. I share how I am feeling with at least one friend or my partner.
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily

8. I sleep well and get at least seven hours of sleep a night.
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily
9. I am careful about what I eat and eat a balanced diet.
   (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily

10. I drink at least 1.5 liters of water (approx. 3 pints) a day.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

11. I laugh without malice or cynicism.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) At least once a day

12. When I leave work at the end of the day I can disengage and leave the pressures of work behind.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

13. I listen to my body’s signals and recognize when I am becoming tired, rundown and vulnerable to illness.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

14. There are people who care about me that I trust, to whom I can talk if I want.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

15. I do something I find creative or expressive (e.g., writing, cooking, gardening etc).
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Daily

16. I feel I have the training and skills I need to do my job well.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

17. I set and maintain healthy boundaries for myself by standing up for myself, saying “no” when I need to, and not letting others take advantage of me.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

18. At work I take a brief break at least every two hours, and switch tasks regularly so that I don’t become too drained.
    (0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

19. I spend time with groups of people I trust and to whom I feel close who are part of a community of meaning and purpose (e.g., a church group, a group of volunteers, work colleagues).
    (0) Never / (1) Seldom / (2) Sometimes / (3) About once a week / (4) More than once a week

20. My ability to communicate with other is…
(0) Very poor / (1) Poor / (2) Fair / (3) Good / (4) Excellent

21. I feel good about how I spend my time and energy in relation to what is really important to me in life
(0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

22. I believe in myself and generally give myself positive messages about my ability to accomplish my goals – even when I encounter difficulties
(0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

23. I set realistic goals for my life (both short term and long term) and work towards them consistently.
(0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Always

24. I take good vacations (at least one two-week vacation every year).
(0) Never / (1) Seldom / (2) Sometimes / (3) Often / (4) Every year

25. I drink alcohol, smoke, or use other recreational drugs
(0) Three or more times every day / (1) At least once every day / (2) Three to six times a week / (3) Less than three times a week / (4) Never

TOTAL SCORE: ____________

Interpretation guidelines

0-25: A score in this range suggests that your self care skills and lifestyle balance strategies may be poor, and that you could possibly benefit from developing a plan to change your lifestyle and improve your self-care.

26-50: A score in this range suggests that your self care skills and lifestyle balance strategies may be poor to average, and that you could possibly benefit from developing a plan to improve your self-care.

51-75: A score in this range suggests that you may have moderately good self-care skills and lifestyle balance strategies in place.

76-100: A score in this range suggests that you may have good self-care skills and lifestyle balance strategies in place.
Guided Meditation Script Part 1
Introductory Relaxation

Find yourself a quiet place to sit. Turn off your phone and dim the lights. This is your time. A
time for total relaxation and inner stillness.

Take a moment to make sure that you are warm enough, and that you are seated comfortably.
Rest your hands loosely in your lap. Now close your eyes.

Take a long slow, deep breath in...hold it for a moment, and then slowly exhale.

Just allow any tension to melt away as you gradually relax more and more deeply with each
breath.

Take another long slow, deep breath in...hold it, and then exhale. Empty your lungs completely
with your out-breath.

Take a third deep breath in. Take your time. Hold it for a moment, and then let it go.

Already you are beginning to drift into a state of deep relaxation.

Continue to breathe slowly and gently.

Relax.

Now bring your awareness to the top of your head.

Sense or imagine a feeling of relaxation beginning to spread down from the top of your scalp....

Let the muscles in your forehead and temples relax.

Allow your eyes to relax.

Let your cheeks and jaw soften and let go of all tension.

Now this peaceful feeling flows down your neck and deep into the muscles in your
shoulders...soothing them...releasing them.

Breathe.

Allow this peaceful feeling to flow through your arms. Relaxing and soothing...all the way to the
tips of your fingers.

As your body relaxes, your mind relaxes. Your thoughts become weightless, like wisps of clouds
on the breeze.

Now the peaceful sensation flows through your chest and your stomach. Feel how this area gently
rises and falls as you breathe...slowly and deeply. Soothing and relaxing.

Turn your attention to your back, and feel this relaxing sensation flow all the way down your
spine.
Now the peaceful feeling flows through your lower body.

Relax your buttocks...the back of your thighs...the front of your thighs. Feel all these large, strong muscles becoming loose and relaxed.

Soothing feelings flow down through your knees, and into your calves.

Your ankles relax. Now your feet relax.

Your entire body is soft, calm and relaxed.

Now it’s time to leave the external world behind, and go on an inner journey. A journey to a place of deep inner stillness.

**Guided Meditation Script Part 2**

**The Inner Journey**

Imagine that you are standing on a white sandy beach.

It’s early in the morning, and a light, hazy mist surrounds you.

The sun is rising slowly. You can feel the warm, orange light on your face and your body.

You are feeling content. At ease. Relaxed.

The sand beneath your bare feet is soft and warm.

A light breeze caresses your face.

This beach is deserted. You have it all to yourself, and you have all the time in the world.

Listen to the relaxing sound of the ocean. Its waves are breaking gently on the shore.

Begin to walk slowly through the mist towards the water.

A small boat is waiting for you. The boat is comfortable and steady. Notice that it is tied to the shore with a strong rope.

Walk to the water’s edge and step into the boat.

You are feeling completely at peace, completely safe, and completely relaxed.

When you are ready, untie the rope...and let it go.

Relax, and allow the natural currents of the ocean to guide you away from the beach.

Your boat drifts smoothly. It rocks ever so gently in the water. This rocking motion relaxes you even more deeply.

The sun is now higher in the sky. Its light has gathered strength.

Notice that the mist that surrounds you is beginning to evaporate.
You can see the air becoming clearer and clearer.

Watch as the sun’s rays dissolve all of the mist. Now you can see clearly in all directions. It’s as though a veil has been lifted.

Sparkling ocean water surrounds you on all sides, and in front of you, a small island comes into view.

Your boat moves closer and closer to the island, gliding slowly and effortlessly through the water.

The island is drenched in sunlight. It is covered in tropical palm trees that sway gently in the breeze.

Your boat glides slowly forward, and comes to rest on the shore.

You have arrived.

Step out of the boat and take a moment to appreciate this place of sublime beauty.

Exotic birds dance from tree to tree, and brilliantly coloured flowers grow in abundance.

The air itself seems to shimmer and vibrate with pure, luminous energy.

You can hear the soothing sound of the wind as it passes through the trees.

In this place, you are free from all memories of the past. You are free from all concerns about the future. You are free from all responsibilities.

This is a place of total peace, and it is all yours.

You notice an opening between the palm trees. In the centre of this opening, there is a narrow path that leads deep into a rich green forest.

Begin your journey into the heart of the forest. Follow the path as it meanders between columns of ancient trees.

This forest seems familiar to you, like the memory of a pleasant dream, or a place you visited as a child.

Walk deeper into the forest. You are guided by a force that you trust, and that makes you feel safe, nurtured and still.

You have reached the very heart of the forest. Before you is a shimmering pond of crystal clear water. A pond of perfect stillness.

The pond is round, and it brims with pure spring water.

Notice that the water is perfectly still, like a mirror, free from even the slightest ripple.

A ladder with three steps leads down into the water.

You decide to bathe in this magical pond, and you undress.
As you take the first step down into the pond, you notice that the wind has eased. All the trees have become motionless.

As each moment passes, the world around you becomes more and more calm, and you yourself become more and more still.

As you lower yourself onto the second step, all the birds in the forest become quiet. Their silence is deep and reverent.

Now lower yourself onto the third and final step and glide into the water.

Feel yourself sliding into a deep state of relaxation. In this pond, your thoughts simply melt away.

All is still and silent. The only sound that remains is the sound of waves, far off in the distance.

Your mind seems to expand. You feel timeless...vast...empty...relaxed.

For the next few minutes, enjoy this experience of solitude and inner silence. When thoughts arise, simply let them go and return your awareness to the sound of the waves. When it’s time to return I will guide you home.

The guided meditation now pauses to allow for approximately 5 minutes of inner silence.

Autism Poems

“I Am Ethan”

I am Ethan.
You may not understand me, or the way I feel today.
You may not understand my reasoning for things I do or say.

The reasons why I'm so loud and say things over & over again,
Why I run so differently or lose my homework every now & then.

I write my letters backwards and sometimes numbers too,
and when in a conversation, I'll say "Guess what" 100 times to you.

Too much noise, light, or excitement can set me in a spin.
I don't like the way these pants feel rubbing against my skin.

I try to be good, but sometimes it's hard to control,
I have to do it, it's an impulse, I don't always do what I'm told.

Ketchup, Ranch and BBQ sauce on everything I eat,
sometimes I have days that I just can't sit still in my seat.

I like to talk a lot even when it's out of turn,
my mind plays tricks on me and interrupts what I'm trying to learn.

Sit up straight, wipe my face, and play ever so soft,
some of these things I have trouble with and I usually lose my train of thought.

I didn't mean to spill the milk mom, or slam the door so hard,
everyone else is done with their homework, I don't know where to start?

My heart's as big as gold, my feelings get hurt too,
I get sad, cry and have bad days just like you.

My brain works differently than other girls and boys,
but one thing always holds true, I can give your life so much joy.

I get frustrated so easily and my hand won't work that way,
I don't understand why those other kids won't let me come over and play.

Please don't think of me any differently or love of me any less,
I'm just like other kids and trying to do my best.

I am very special in my own unique way, and every moment with me
you'll never have a dull day.

By Kelly Graham
“Blessed Are Those”

I. Blessed are those who stop and listen to my chatter. You may not understand me; but I love when people talk to me, for I long for companionship, too.

II. Blessed are those who take my hand and walk with me when the path is rough, for I easily stumble and grow weary. But thank you, too, for letting me walk alone when the path is smooth, for I must learn independence.

III. Blessed are those who take the time to tell me about special happenings, for unless you make special effort to inform me, I remain ignorant.

IV. Blessed are those who wait for me. I may be slow, but I appreciate your patience.

V. Blessed are those who are not ashamed to be seen in public with me, for I did not choose to be born thus. It could have been you as well.

VI. Blessed are those who do not pity me, for I don't want pity. All I want is understanding and respect for what I have learned as well.

VII. Blessed are those who notice my accomplishments, small as they may seem to you. I must work long and hard to learn many of the things you take for granted.

VIII. Blessed are those who include me in their games, even though I may not understand the rules, I still like to be included in your activities.

IX. Blessed are those who think of me as a person who loves, and hurts, and feels joy and pain just like you do, for in that respect I am normal.

Author Unknown
“Before I Go To Sleep…”

Mommy, don't you cry now and Daddy don't you weep.
I want to whisper something before I go to sleep.
I know that when I came here I looked perfect in every way.
And you were so proud, Daddy; when you held me on that day.
And Mommy, when you kissed me and wrapped me up so tight,
I knew that I belonged here and everything was right.
But then I stopped talking and began to slip away,
I saw your worried faces as you knelt by me to pray.
And Daddy, I always notice how you wipe away a tear.
When you watch the other children as they run and laugh and cheer.
I may not be able to tell you how much I love you so,
Or even show you how I feel and what I really know.
But when you hold me, Mommy, at night when all is still,
I feel the love you have for me and I know that all is well.
And Daddy, when you take me to the park to run and play
I know that you still love me thought the words I cannot say.
I want to tell you something before I go to sleep.
I may be sort of direct and you may not understand,
I know that I am not that little child that you and Daddy planned.
But I love you both so very much and I know you love me too,
And if I could only speak my heart, you would feel my love for you.
I know the future is unknown and you will always have to be,
The ones who love and listen and take good care of me.
I know that you are frightened and you shed so many tears,
And if I could I'd wipe them dry and take away your fears.
So Mommy, don't you cry now and Daddy please don't weep.
I want to say…I love you both, before I go to sleep.

Written by Sally Meyer, 2000
I am the mother of an autistic child.
It is not easy from day to day.
I know that with hard work,
my son and I are going to be okay.

He goes to school and therapy.
He works as hard as he can.
He fights this thing we call autism.
We are proud of our little man.

We are turning a negative into a positive.
Everyday that is what we do.
Our glass if half full instead of empty.
And it can be that way for you too.

So don't give up. Don't fall apart.
We'll all make it through with
determination and heart.

Our kids are special, and that's a fact.
We can fight autism, and get what it takes back.
“I Am Autism”

By Marty Murphy

Hello. Allow me to introduce myself to you. My name is autism. Perhaps you know me or know of me. I am a condition, "disorder" that affects many people. I strike at will, when and where I want. Unlike Downs Syndrome or other birth "defects," I leave no marks on those I strike. In fact, I pride myself on the ability to infiltrate a child's life, while leaving him or her strikingly handsome. Many people may not even know I am there. They blame the child for what I cause him or her to do. I am autism and I do as I please.

I am autism. I strike boys and girls. Infants and toddlers. I find my best victims to be boys around the age of 2, but any child will do. I like children and they are always the true victims, though I take hostage the others in the child's family as well. It is a bit like getting two for the price of one. I affect one child and "infect" the entire family.

I am autism. I strike rich and poor alike. The rich combat me with education and therapy. The poor shut their children away and cannot afford to fight me. I am able to win in the lives of poor children more than I am those of the wealthy, but I will try to take root anywhere.


I am autism. I do not discriminate based upon religion either. I strike Jews and Christians, Muslims and Buddhists, Atheists and Agnostics. I do not care what religion a person is or what beliefs he may hold. When I strike, there will be little time for any of that anyway. When they find me, they will question everything they believe in, so why would I strike only one group? I have affected followers of every religion on the planet.

I am autism and I am strong and getting stronger every year, every month, every day, every minute and every second. I am concerned that money might be allotted to combat me and my takeover of children, but so far, I have little to fear. Some countries like Kuwait, are spending quite a bit of money to assist those who I have targeted and some, like the United States, would rather spend money on such ludicrous things as discovering the number of American Indians who practice Voodoo, as opposed to combating me. In an atmosphere such as that, I can flourish and wreak havoc at will. In places such as that, I rub my hands with glee at the problems I can cause to children, their families and to the society at large.

I am autism. When I come, I come to stay. I take the dreams and hopes of families and trample them with delight. I see the fear and confusion in the eyes of my victims and see the formation of wrinkles, the worries and pain on the face of their parents. I see the embarrassment their child causes because of me and the parents unsuccessful attempt to
I am autism. I take speech and learning. I take socialization and understanding. I take away "common sense" and, if I am allowed to flourish, I take away all but their physical life. What I leave behind, is almost worse than death.

I am autism. I fear nothing except courage, which I thankfully see little of. I fear those who take a stand against me and attempt to fight me and bring others into the fight as well. I fear those who try to make it safe and easier for my victims in the community, and their families. I fear those who push ahead, despite the fact that I am in tow. I fear the day I will be eradicated from the planet. Yet, I do not fear too much right now. There is no need.

I am autism and I bet you know me or know of me. If you don't, you probably will soon. I am marching forward faster than I ever have before. I am looking for new children all the time. I am looking for new children to consume and new lives to destroy. I dread the day I will be looked upon with pity or worse yet, understanding, for that day, is the day I will begin to die.

But in the mean time I am safe, free to prowl onward. Free to cause the pain and suffering that I do so well. I am on a mission and have much work to do and thankfully no one is stopping me yet.

Hello. Allow me to introduce myself. My name is autism. Perhaps you know me or know of me, if not don't worry, you will meet me soon.
“A Special Drop of Love”

A special drop of love was deposited in my womb with care
The unconditional love you give to me is so very rare
When you were born, Oh! What a glorious day!

I never knew there could be a love so strong
I am so blessed, because in my heart there is a song
A song of peace and assurance
A song of strength and endurance
When I look into your eyes, my heart feels your love
A Special Drop of Love came from heaven above

Your smile gives your face that special glow
Whenever you look at me, my love for you continues to grow
The Hugs! The Kisses!
These are moments of pure gold
They are treasures I have hidden deep within my soul
Many told me you would not make it this far
But look at you now, gleaming like a shining star
Every sound you make is like music to my ears
The look you give me helps wipe away my tears

Many have wondered, "Why me?"
I looked at you and wondered, "Don't they see what I see?"
Many have wondered, "What am I going to do?"
But when I look at you, I know I can make it through
Yes, I get tired sometimes and the tears begin to flow
But then you reach for my hand and that's when I know
That healing comes after the pain
And the sun comes after the rain

God trusted me with such a treasure
The joy I feel is beyond measure
As each day turns into night
I feel the strength to continue to fight
As each night turns into day I know that God hears every prayer I pray
My hopes and my dreams are far beyond me
Your encouragement and joy allows me to be free

A Special Drop of Love came from above
A precious little package for me to LOVE
I know I am strong and can conquer any trial
When I look in your face and see your smile

Written by Bishop Helen E. London
“Where Are The Parents?”

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents? They are at home, diapering their 15 year old son, or trying to lift their 100 lb. daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents? They are sitting, blearly eyed and exhausted, in hospital emergency rooms, waiting for tests results to come back and wondering: is this the time when my child doesn't pull through? They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ. They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents? They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm. They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of their own.

Where are the parents? They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer. They are working 2 and sometimes 3 jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents? They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything. They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families. They are busy, trying to survive.
Written by Sue Stuyvesant

Source: http://www.child-autism-parent-cafe.com
100 Benefits of Meditation

There are so many advantages to meditation. Meditation is a powerful tool that can help improve the quality of life for individuals and can even help people live longer, and best of all, it’s FREE! Here is the definitive list of benefits that meditation can provide you with:

**Physiological benefits:**
1- It lowers oxygen consumption.
2- It decreases respiratory rate.
3- It increases blood flow and slows the heart rate.
4- Increases exercise tolerance.
5- Leads to a deeper level of physical relaxation.
6- Good for people with high blood pressure.
7- Reduces anxiety attacks by lowering the levels of blood lactate.
8- Decreases muscle tension
9- Helps in chronic diseases like allergies, arthritis etc.
10- Reduces Pre-menstrual Syndrome symptoms.
11- Helps in post-operative healing.
12- Enhances the immune system.
13- Reduces activity of viruses and emotional distress
14- Enhances energy, strength and vigour.
15- Helps with weight loss
16- Reduction of free radicals, less tissue damage
17- Higher skin resistance
18- Drop in cholesterol levels, lowers risk of cardiovascular disease.
19- Improved flow of air to the lungs resulting in easier breathing.
20- Decreases the aging process.
21- Higher levels of DHEAS (Dehydroepiandrosterone)
22- prevented, slowed or controlled pain of chronic diseases
23- Makes you sweat less
24- Cure headaches & migraines
25- Greater Orderliness of Brain Functioning
26- Reduced Need for Medical Care
27- Less energy wasted
28- More inclined to sports, activities
29- Significant relief from asthma
30- improved performance in athletic events
31- Normalizes to your ideal weight
32- harmonizes our endocrine system
33- relaxes our nervous system
34- produce lasting beneficial changes in brain electrical activity
35- Cure infertility (the stresses of infertility can interfere with the release of hormones that regulate ovulation).
Psychological benefits:
36- Builds self-confidence.
37- Increases serotonin level, influences mood and behaviour.
38- Resolve phobias & fears
39- Helps control own thoughts
40- Helps with focus & concentration
41- Increase creativity
42- Increased brain wave coherence.
43- Improved learning ability and memory.
44- Increased feelings of vitality and rejuvenation.
45- Increased emotional stability.
46- improved relationships
47- Mind ages at slower rate
48- Easier to remove bad habits
49- Develops intuition
50- Increased Productivity
51- Improved relations at home & at work
52- Able to see the larger picture in a given situation
53- Helps ignore petty issues
54- Increased ability to solve complex problems
55- Purifies your character
56- Develop will power
57- greater communication between the two brain hemispheres
58- react more quickly and more effectively to a stressful event.
59- increases one’s perceptual ability and motor performance
60- higher intelligence growth rate
61- Increased job satisfaction
62- increase in the capacity for intimate contact with loved ones
63- decrease in potential mental illness
64- Better, more sociable behaviour
65- Less aggressiveness
66- Helps in quitting smoking, alcohol addiction
67- Reduces need and dependency on drugs, pills & pharmaceuticals
68- Need less sleep to recover from sleep deprivation
69- Require less time to fall asleep, helps cure insomnia
70- Increases sense of responsibility
71- Reduces road rage
72- Decrease in restless thinking
73- Decreased tendency to worry
74- Increases listening skills and empathy
75- Helps make more accurate judgements
76- Greater tolerance
77- Gives composure to act in considered & constructive ways
78- Grows a stable, more balanced personality
79- Develops emotional maturity
**Spiritual benefits:**
80- Helps keep things in perspective
81- Provides peace of mind, happiness
82- Helps you discover your purpose
83- Increased self-actualization.
84- Increased compassion
85- Growing wisdom
86- Deeper understanding of yourself and others
87- Brings body, mind, spirit in harmony
88- Deeper Level of spiritual relaxation
89- Increased acceptance of oneself
90- helps learn forgiveness
91- Changes attitude toward life
92- Creates a deeper relationship with your God
93- Attain enlightenment
94- greater inner-directedness
95- Helps living in the present moment
96- Creates a widening, deepening capacity for love
97- Discovery of the power and consciousness beyond the ego
98- Experience an inner sense of “Assurance or Knowingness”
99- Experience a sense of “Oneness”
100- Increases the synchronicity in your life

Meditation is completely FREE! It requires no special equipment, and is not complicated to learn. It can be practiced anywhere, at any given moment, and it is not time consuming (15-20 min. per day is good). Best of all, meditation has NO negative side effects. Bottom line, there is nothing but positive to be gained from it! With such a huge list of benefits, the question you should ask yourself is, “why am I not meditating yet?”

Source: [http://www.ineedmotivation.com/blog/2008/05/100-benefits-of-meditation/](http://www.ineedmotivation.com/blog/2008/05/100-benefits-of-meditation/)
The Effects of Stress

Physical or mental stresses may cause physical illness as well as mental or emotional problems. Here are parts of the body most affected by stress.

Hair:
High stress levels may cause excessive hair loss and some forms of baldness.

Brain:
Stress triggers mental and emotional problems such as insomnia, headaches, personality changes, irritability, anxiety and depression.

Mouth:
Mouth ulcers and excessive dryness are often symptoms of stress.

Heart:
Cardiovascular disease and hypertension are linked to accumulated stress.

Lungs:
High levels of mental or emotional stress adversely affects individuals with asthmatic conditions.

Reproductive organs:
Stress affects the reproductive system causing menstrual disorders and recurrent vaginal infections in women and impotence and premature ejaculation in men.

Muscles:
Spasmodic pains in the neck and shoulders, musculoskeletal aches, lower back pain, and various minor muscular twitches and nervous tics are more noticeable under stress.

Digestive tract:
Stress can cause or aggravate diseases of digestive tract including gastritis, stomach and duodenal ulcers, ulcerative colitis, and irritable colon.

Skin:
Some individuals react to stress with outbreaks of skin problems such as eczema and psoriasis.
Family Caregiving Tips: Attend to your own needs

Emotional needs of family caregivers

- **Take time to relax daily** and learn how to regulate yourself and de-stress when you start to feel overwhelmed.
- **Keep a journal.** Write down your thoughts and feelings. This will give you perspective and serve as a way to release strong feelings.
- **Talk with someone** to make sense of your situation and your feelings.
- **Feed your spirit.** Pray, meditate, or do another activity that makes you feel part of something greater. Try to find meaning in your life and in your role as a caregiver.
- **Watch out for signs of depression and anxiety,** and get professional help if needed.

Social & recreational needs of family caregivers

- **Stay social.** Make it a priority to visit regularly with other people. Nurture your close relationships. Don’t let yourself become isolated.
- **Do things you enjoy.** Laughter and joy can help keep you going when you face trials, stress, and pain.
- **Maintain balance in your life.** Don’t give up activities that are important to you, such as your work or your hobbies.
- **Give yourself a break.** Take regular breaks from caregiving, and give yourself an extended break at least once a week.
- **Find a community.** Join or reestablish your connection to a religious group, social club, or civic organization. The broader your support network, the better.

Physical needs of family caregivers

- **Exercise regularly.** Try to get in at least 30 minutes of exercise, three times per week. Exercise is one of the best ways to relieve stress and boost your energy. So get moving, even if you’re tired.
- **Eat right.** Well-nourished bodies are better prepared to cope with stress and get through busy days. Keep your energy up and your mind clear by eating nutritious meals at regular times throughout the day.
- **Avoid alcohol and drugs.** It can be tempting to turn to substances for escape when life feels overwhelming. But they can easily compromise the quality of your caregiving. Instead, try dealing with problems head on and with a clear mind.
- **Get enough sleep.** Aim for an average of 8 hours of solid, uninterrupted sleep every night. Otherwise, your energy level, productivity, and ability to handle stress will suffer.
- **Keep up with your own health care.** Go to the doctor and dentist on schedule, and keep up with your own prescriptions or medical therapy. As a caregiver, you need to stay as strong and healthy as possible.
WORKSHOP EVALUATION QUESTIONNAIRE

Workshop Name: ____________________________________
Training Location: ____________________________________
Participant Name (optional): ___________________________
Date: _______________

INSTRUCTIONS
Please circle your response to the items. Rate aspects of the workshop on a 1 to 5 scale:
1 = "Strongly disagree," or the lowest, most negative impression
3 = "Neither agree nor disagree," or an adequate impression
5 = "Strongly agree," or the highest, most positive impression

Choose N/A if the item is not appropriate or not applicable to this workshop. Your feedback is sincerely appreciated. Thank you!

WORKSHOP CONTENT (Circle your response to each item.)
1=Strongly Disagree 2=Disagree 3=Neither agree nor disagree 4=Agree
5=Strongly Agree N/A=Not applicable

1. I was well informed about the objectives of this workshop. 1 2 3 4 5 N/A

2. This workshop lived up to my expectations. 1 2 3 4 5 N/A

3. I found the content to be relevant to my life. 1 2 3 4 5 N/A

WORKSHOP DESIGN (Circle your response to each item.)

4. The workshop objectives were clear to me. 1 2 3 4 5 N/A

5. The workshop activities stimulated my learning. 1 2 3 4 5 N/A

6. The pace of this workshop was appropriate. 1 2 3 4 5 N/A

WORKSHOP INSTRUCTOR (FACILITATOR) (Circle your response to each item.)

7. The instructor was well prepared. 1 2 3 4 5 N/A

8. The instructor was helpful. 1 2 3 4 5 N/A
9. The instructor demonstrated knowledge on the topic of the workshop. 1 2 3 4 5 N/A

**WORKSHOP RESULTS** (Circle your response to each item.)

10. I accomplished the objectives of this workshop. 1 2 3 4 5 N/A

11. I will be able to use what I learned in this workshop. 1 2 3 4 5 N/A

**SELF-PACED DELIVERY** (Circle your response to each item.)

12. The workshop was a good way for me to learn this content. 1 2 3 4 5 N/A

13. How would you improve this workshop? (Check all that apply.)

  ___ Provide better information before the workshop.
  ___ Clarify the workshop objectives.
  ___ Reduce the content covered in the workshop.
  ___ Increase the content covered in the workshop.
  ___ Update the content covered in the workshop.
  ___ Improve the instructional methods.
  ___ Make workshop activities more stimulating.
  ___ Improve workshop organization.
  ___ Make the workshop less difficult.
  ___ Make the workshop more difficult.
  ___ Slow down the pace of the workshop.
  ___ Speed up the pace of the workshop.
  ___ Allot more time for the workshop.
  ___ Shorten the time for the workshop.

14. What other improvements would you recommend for this workshop? ____________________________________________

15. What was least valuable about this workshop? __________________________________________________________

16. What was most valuable about this workshop? __________________________________________________________
Are you interested in receiving information on upcoming workshops or information on future events catering to children with autism and their families?

Yes No

If so, please write your name, address, e-mail, and phone number below:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Resources:

**Autism Speaks**
6330 San Vicente Blvd., Suite 401
Los Angeles, CA 90048
Phone: (323) 549-0500
Fax: (323) 549-0547
[www.autismspeaks.org](http://www.autismspeaks.org)

**Autism Society of America, Los Angeles**
8939 S Sepulveda Blvd.,
Suite 110-788
Los Angeles, CA 90045
Phone: 562-804-5556
Fax: 562-425-4940
[http://autismla.org](http://autismla.org)

**The Help Group**
Phone: 877-994-3585
Fax: 818-779-5295
[www.thehelpgroup.org](http://www.thehelpgroup.org)

**Groupworks West**
11140 Washington Blvd.
Culver City, CA 90232
Phone: 310-287-1640
Fax: 310-287-0851
[www.groupworkswest.com](http://www.groupworkswest.com)

**Autism Research Institute**
4128 Adams Avenue
San Diego, CA 92116
Phone: 866-366-3361
[www.autism.com](http://www.autism.com)

**Los Angeles Families for Effective Autism Treatment (LA FEAT)**
4733 Torrance Blvd #804
Torrance, CA 90503
Email: info@lafeat.org
[www.lafeat.org](http://www.lafeat.org)
UCLA Center for Autism Research and Treatment (CART)
Semel Institute, Room 68-237
760 Westwood Plaza
Los Angeles 90095
Tel: 310-794-4008
Fax: 310-825-5197
Email: clinic@autism.ucla.edu
http://www.semel.ucla.edu/autism

Cure Autism Now
5225 Wilshire Blvd. #503
Los Angeles, CA 90036
Phone: 213-549-0547
www.cureautismnow.org

Behavior and Education Inc.
ABA Intervention Services
15260 Ventura Boulevard, Suite 1200
Sherman Oaks, CA 91403
Phone: 310-406-1500
Fax: 310-406-1531
Email: contact@behaviorandeducation.com
http://behaviorandeducation.com

Behavioral Education for Children with Autism (BECA)
369 Van Ness Way, Suite 710
Torrance, CA 90501
Phone: (310) 517-8505
Email: kmorris@beca-aba.com
http://beca-aba.com

Autism Movement Therapy
Phone: 323.240.0361
Contact: Joanne Lara
http://www.autismmovementtherapy.org

Autism Meet-up
World's largest network of local groups
http://autism.meetup.com
North Los Angeles County Regional Center
15400 Sherman Way, Suite 170
Van Nuys, CA 91406-4211 USA
Phone: (818) 778-1900
Fax: (818) 756-6140
www.nlacrc.org/

Frank D. Lanterman Regional Center
3303 Wilshire Boulevard, Suite 700
Los Angeles, CA 90010 USA
Work (213) 383-1300
Fax (213) 383-6526
www.lanterman.org/

Find a Therapist:

Network Therapy – A Mental Health Network and Directory
www.networktherapy.com

Psychology Today
The Therapy Directory
http://therapists.psychologytoday.com

Debbie Dery, M.S., MFT
16001 Ventura Blvd. #125
Encino, CA 91436
818-754-1526

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818- 272-8755

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Tarzana, California 91356
818-924-3960

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21134 Costanso Street
Woodland Hills, California 91364
516- 986-2988

Dr. Anita Bavarsky, yDPs
23123 Ventura Blvd.
Suite 207
Woodland Hills, California 91364
818- 340-4999