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**WE C.A.R.E 2: a parent-child
community yoga program that promotes
the health and well-being of caregivers
and their children autism spectrum disorder**

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BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**WE C.A.R.E. 2:
A PARENT-CHILD COMMUNITY YOGA PROGRAM THAT PROMOTES
THE HEALTH AND WELL-BEING OF CAREGIVERS AND THEIR
CHILDREN WITH AUTISM SPECTRUM DISORDER**

by

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requirements for the degree of
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DEDICATION

I would like to dedicate this work to my husband Ray and our children Christae, Kerri, and Ray, for their continuous support and love. I would also like to dedicate this work to and all parents, including my own parents, for taking that leap of faith into parenthood and persevering and growing throughout the journey.

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when the seas got rough. Our children, Christae, Kerri, and Ray III, for adding to the support, strength, and love that motivated and humbled me to move forward and evolve as a human being. My family, siblings and their spouses, as well as my nieces, Heather and Deidre, have continually taught me about the true meaning of family with their love, support and humor.

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ABSTRACT

The prevalence of autism spectrum disorder (ASD) has increased two percent from 2012–2014 (Centers for Disease Control and Prevention, 2018) and the Centers of Disease Control and Prevention (CDC) has considered ASD to be a major health concern. The demands of caring for a child with developmental disabilities, including ASD can be overwhelming and the caregivers are experiencing heightened levels of stress in comparison to rearing typically developing children (Argumedes, Lanovaz, & Larivée, 2017; Lindo, Kliemann, Combes, & Frank, 2017). There is a need for more family support to implement more effective coping strategies to deal with the maladaptive functioning of the child with ASD (Hall, & Graff, 2011).

The WE C.A.R.E. 2 Program is a nine-week evidence-based community pilot program that will provide an inclusive opportunity with additional family support and effective coping strategies e.g., breathing techniques, yoga postures and positive coping cognitions (e.g., positive self-talk and reappraisals) to decrease the stress levels of caregivers and promote healthy behaviors and healthy child development with the

support and training from trained facilitators and a network of caregivers. This individualized plan will tailor to the needs of each dyad to create the necessary mechanisms of change (behavior, cognition, physiological, and sensory modulation) among the children and adults in the yoga group. The professional collaboration of different disciplines (occupational therapy, yoga therapist and teacher) will provide the appropriate modifications to the environment and provide the necessary input for the “just right” experience for a positive outcome.

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LIST OF ABBREVIATIONS

ACOTE	Accreditation Council for Occupational Therapy Education
AJOT	American Journal of Occupational Therapy
AOTA	American Occupational Therapy Association
ASD	Autism Spectrum Disorder
BPT	Behavioral parent Training
C.A.R.E.	Compassion, awareness, respect, and engagement
CDC	Centers for Disease Control and Prevention
CNS	Central Nervous System
CSI	Coping Skills Intervention
DBD	Disruptive behavior disorders
DD	Developmental disabilities
EBIs	Evidenced-Based Interventions
FCP	Family-Centered Practice
FSL	Family Service League
NFT	Neurofeedback
NHA	Nurtured Heart Approach
NIH	National Institute of Health
NHIS	National Health Interview Survey
HRQOL	Health Related Quality of Life
HR	Heart Rate
HRV	Heart Rate Variability

NCCIH	National Center for Complementary and Integrative Health
NICE	National Institute of Health and Care Excellence
NGO	Non-governmental Organization
NYSOTA	New York State Occupational Therapy Association
OT	Occupational Therapy
OTA	Occupational Therapy Assistants
QoL	Quality of Life
SCT	Social Cognitive Theory
TT	Turn Taking
UDL	Universal Design for Learning
VVC	Ventral Vagal Complex
WHO	World Health Organization

CHAPTER ONE - Introduction

The prevalence of autism spectrum disorder (ASD) has increased two percent from 2012 14.8% in 2012 to 16.8% in 2014 (Centers for Disease Control and Prevention, 2018). According to the Centers for Disease Control and Prevention (CDC), approximately one of every sixty-eight children, eight years of age, (per 1000 children) is diagnosed with ASD and the CDC considers ASD to be a major health concern. ASD is characterized by impairments in social interactions and verbal and non-verbal communication (American Psychiatric Association, 2013). This is a complex and lifelong developmental disability, where symptoms and severity vary from person to person (Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2017; CDC, 2018). This has had an impact on a person with ASD's communication, social skills, and behavior. The complexity and uniqueness of symptoms (e.g., imitation, shared attention, difficulty relating to people, things and events, social interaction and communication problems, and hyper- or hyperactivity to sensory experiences and restricted and repetitive patterns of behaviors) among children with ASD has extended onto their families (American Psychiatric Association, 2013). The communication and social impairments can lead to isolation and can heighten co-morbid conditions such as depression and anxiety in children with ASD and their caregivers (Schiltz, 2018; Blainey, 2017). This has had an impact on the parent-child bond and the well-being of the parent and the family as a whole (Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez,, & Navarro-Peña, 2016; Todd, Bromley, Ioannou, Harrison, Mellor, Taylor, & Crabtree, 2010; Weiss & Lunskey, 2011; Weiss, Cappadocia., MacMullin,

Viecili, & Lunsky., 2012; White, McMorris, Weiss, & Lunsky, 2012). Recent studies have found associations between higher parenting stress levels and psychological distress when raising children with ASD in comparison to rearing typically developing children (Weiss et al., 2012; Weiss, et al., 2014). The three major stressors that have an impact on the parent's ability to cope with their child are the severity of the child's disability, child's caretaking demands, and the maladaptive behaviors of their child (Pastor-Cerezuela et al., 2016). The more maladaptive behaviors the child exhibits the higher the stress levels of the parent or caregiver. The higher the stress levels the less confident and in control the caregiver feels about their ability to handle their child's maladaptive behaviors and their role as a parent. There is a lack of effective interventions and resources for children with ASD and their families to address the core problems and a lack of professional support for parents within the community (Dunst, Trivette, & Cross, 2007). There is a need for more community-based interventions that focus on family-centered care for more positive outcomes (Dunst et al., 2012; Kuhaneck, Madonna, Novak, & Pearson, 2015). According to the National Institute of Health and Care Excellence (NICE), two principles that will enable individuals and communities toward behavior change are to assist families in gaining a sense of more control over situations with the provision of a number of cognitive, social and environmental resources to encourage the resilience of people living in difficult circumstances (NICE, 2007). NICE recognizes the important role that behavior plays in people's health.

All of these problems have played a role in the lack of parent-child relations and the health and wellbeing of the caregiver, which has had an impact on the quality of

family functioning. Community and evidenced-based interventions (EBIs) for families of children with ASD would work toward the improvement of parent-child interactions; increase the parent's level of confidence with their occupation as a parent; improve their feelings of wellbeing; decrease parental stress levels; and improve family functioning.

The key to improving the quality of overall family functioning is minimizing caregiver distress, since negative outcomes for caregivers have been associated to chronic caregiver distress and illness, including co-morbid health conditions such as high blood pressure, anxiety, depression (Bögels & Restifo, 2014). A recent study demonstrated that caregiver stress mediated the relation between ASD symptom severity and maternal psychopathology (Lindsey & Barry, 2018), suggesting that higher levels of stress can lead to more serious mental health concerns (Linsey & Barry, 2018). Linsey & Barry (2018) further demonstrated that a bidirectional relationship exists between the caregiver responses and its effect on the child's ability to handle stressful situations and their reaction to those situations. An association between lower caregiver distress and higher levels of parenting efficacy. There are a number of different ways to reduce or manage stress, which includes the development of awareness (e.g., cognitive) of stressors and coping strategies such as relaxation techniques e.g., biofeedback, meditation, yoga; and the improvement of communication between the caregiver and the child by understanding behavioral style and anxiety reduction techniques (Sharma, 2014; Sharma & Rush, 2014). An emerging field exists in teaching parents to implement strategies to increase their children's communicative and social development, which will fill the gap that exists in providing parent-to-parent and small group support, in order, to maintain and

generalize learned skills (Patterson, Smith, & Mirenda, 2012)

The WE C.A.R.E. 2 program is a nine-week community health promotion program that will involve five dyads, consisting of caregivers and their children with ASD, ages five to eight years of age. This program will address the gap in effective EBIs within the community by providing the support, education, and resources for families and their children with ASD to change the way the behavioral and sensory issues (e.g., hyperactivity, aggression) of their children are addressed and managed, so that they can create more meaningful and productive solutions that are tangible for these increasing and challenging problems.

The resources, tools, and strategies provided throughout the program aims to facilitate and guide the caregiver and their child toward healthy behavior changes such as decreasing stress/anxiety and promoting positive social engagement and family relations through the use of stress management techniques (e.g., different breathing techniques, yoga postures).

CHAPTER TWO – Project Theoretical and Evidence Base

The WE C.A.R.E. 2 (Compassion, Awareness, Respect, and Engagement) Partner Yoga Program is a community-centered health promotion program that provides an inclusive opportunity for caregivers and their children with Autism Spectrum Disorder (ASD) to decrease stress levels, gain a sense of control, and improve their sense of well-being through engagement in partner yoga. Development of the WE C.A.R.E. 2 program was grounded in theories of health and wellbeing and informed by the evidence.

There are a number of theoretical practice models that support the use of compassion, awareness, respect, and engagement in the WE C.A.R.E. 2 Partner Yoga Program. There are four theoretical frameworks that I have chosen to direct and individualize my program to meet the needs of each participant: Wilcock’s Theory of Risk Factors, Universal Design for Learning (UDL), Dunn’s Sensory Model and Bandura’s Social Cognitive Theory (SCT) .

Wilcock’s Theory of Risk Factors:

Wilcock’s Theory of Risk Factors addresses community health and wellbeing. Wilcock’s definition of occupation is based on the premise that “people need, want or have to do” (or proactively engage) for functional purposes (Kosma, Bryant & Wilson, 2013). Kosma et al. (2013) further explains Wilcock’s theoretical concepts by relating the brain’s performance to survive and its role in controlling occupational behaviors. Caregivers of children with ASD can be challenged by the characteristics of their child ‘s diagnosis such as the unusual sensory responses (hypo- and hyper responses) to social and nonsocial stimuli and aggressive behaviors (Baranek,

2002). The We C.A.R.E. 2 program will support and train caregivers and assist them in their role as a parent to become agents of change for their child through the knowledge and practice of more proactive behavioral strategies that can act as self-regulatory tools. These positive coping strategies adaptability of the caregiver can ultimately benefit their child and their ability to be proactive instead of reactive when coping with behavioral deficits and developmental delays (e.g., sensory processing and motor skills). This will empower families, especially caregivers, and assist them in gaining confidence and control when faced with stress situations. The choices that the caregivers and their children make can create occupational balance through the use of self-regulatory techniques that will present the opportunity to participate and engage in real life situations in a way that creates meaning and strengthens bonds. Wilcock considers “doing” as survival and by not “doing” or not becoming engaged as having a greater potential to have an impact the individual’s health and wellbeing (Cole & Tufano, 2007; Kosma et al., 2013). Cole and Tufano (2007) concur with Kosmo (2013) and Wilcox’s theory and the role of occupation in health promotion. Cole and Tufano (2007) further explains the significance of maintenance and enhancement of health and its dependency on occupation; occupation’s place in human life, health, and survival; and defining occupation as doing, being, and becoming as a positive and negative influence on health. This holistic approach is centered on the promotion of health and preventing illness when engaged in real life situations and occupations (Cole & Tufano, 2007). Wilcock’s theory of risk factors is a holistic model that will give the caregivers the support, knowledge, and practice, through engagement and participation, to gain a

sense of control and competency when dealing with the challenging behaviors of their child with ASD.

Universal Design for Learning:

The UDL model describes a framework that can promote the design of environments and the implementation of strategies, within those environments, used to optimize participation of all learners in shared environments, such as schools and communities (Ashburner, Rodger, Ziviani, & Hinder, 2014). This works toward ensuring that the necessary accommodations and adaptations are provided, including sensory properties, in order to create the most optimal environment for all learning styles. The UDL model addresses all learners and consists of three components: engagement, representation, and action & expression. The engagement subset provides options for self-regulation, sustaining effort and persistence, and recruiting interest (Cole & Tufano, 2007; Dunn, 2012). The facilitation of coping skills/strategies and the development of self-reflection falls within the self-regulation subset. Both the child with autism and his/her caregiver will benefit from coping skills that assist in regulating emotions to improve parent-child interaction and positive family relationships. This community-based program provides an opportunity for parents to support and interact with one another. This will promote a sense of well-being that can assist the caregivers in feeling competent in their occupation (caregiver). Occupational therapists practicing in different areas and contexts can utilize universal design principles during site planning and it may be applicable in designing the floor plans for different contexts (e.g., home, school, leisure) when considering the gold standard for maximizing accessibility for all

individuals. The gold standard for universal design of learning are based on seven principles: equitable use (useful design for diverse abilities); flexibility in use (accommodates a wide range of individuals); simple and intuitive (easy to understand); perceptible information (effectively communicates information regardless of conditions or sensory abilities); tolerance for error (minimizes hazards or consequences); low physical effort (use is efficient and comfortable); and size and space is appropriate to accommodate for the individual's size, posture or mobility. Applying universal design principles to the program will increase participation among dyads and individuals and address the individual needs of all participants, so as to improve the quality of parent-child interactions.

Dunn's Sensory Processing Model:

Dunn's Sensory Processing Model addresses the behavioral responses elicited by incoming sensory input from the environment and the different neurological thresholds. In Dunn's Sensory Profile assessment, four processing patterns of neurological thresholds and self-regulation (sensory-seeking, sensory-avoiding, sensory sensitivity, and low registration) are identified (Cole & Tufano, 2007). Dunn considers the four processing patterns as "reflections of who we are" and helps people gain a different understanding of their ability to communicate their needs and take control of their daily occupations (Cole & Tufano, 2007, pp. 232). By understanding and identifying the four processing patterns, occupational therapists can provide the "just right" experience with the necessary sensory input to attend and remain engaged in movement. This will create an environment that fosters proactive engagement and

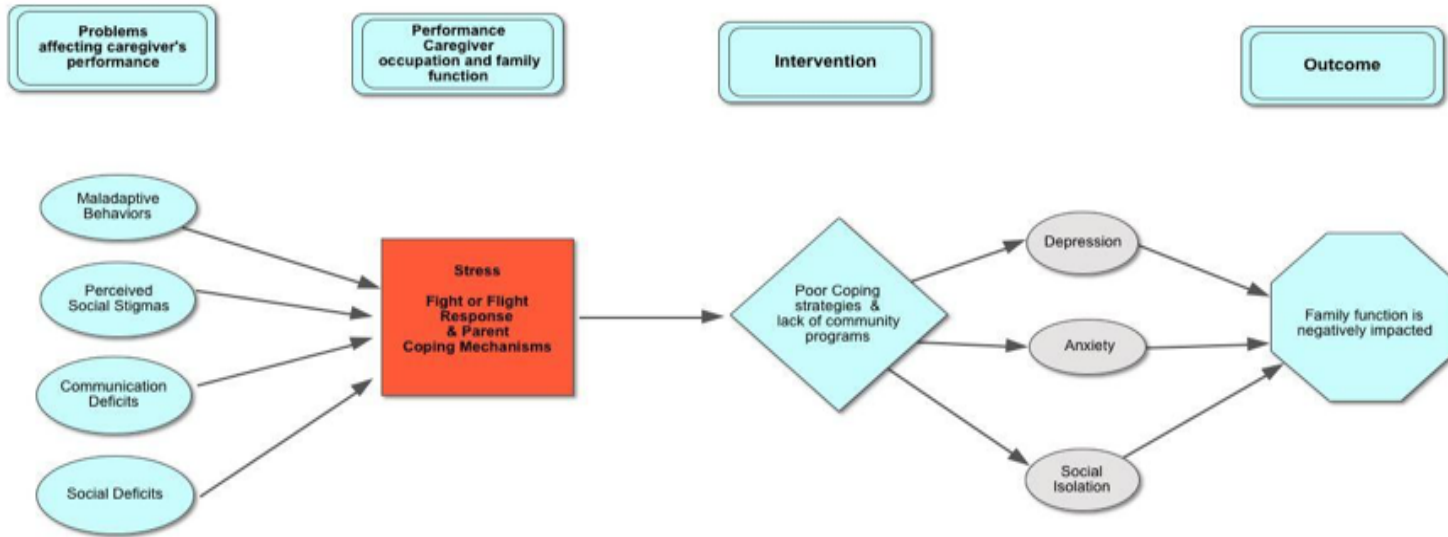
reciprocal interactions for improved family and community functioning. Using this model as a framework will assist the occupational therapist (author and facilitator) in identifying and modifying sensory and environmental barriers that have interfered with the quality and quantity of performance and participation in everyday activities.

Social Cognitive Theory:

Scaffa & Reitz (2014) describes the Social Cognitive Theory (SCT) as one that fosters high- quality relationships through interdependent transactions, called “reciprocal determinism”. Reciprocal determinism occurs when the outcome (health behavior (s)) is related to a continuum of interdependent interactions between the individual’s interaction, behavior, and environment and is conducted in a reciprocal manner. SCT describes the core determinants of health behaviors e.g., knowledge of health risks and benefits of behaviors, perceived self-efficacy, outcome expectations, self-determined health goals and strategies, and the facilitators and barriers to achieve health behavior change (Scaffa & Reitz, 2014). A positive social exchange depends on trust and feeling safe within the environment and situation. This is important when considering the social and sensory deficits and the challenges that children with ASD face in everyday reciprocal interactions and developing and maintaining relationships as a result of these deficits. Parents of children with ASD can gain a positive outcome and improve self-efficacy when they are able to experience past positive interactions as a resource in order to create more positive interactions (exchanges) with their child in the future. The quality of the relationship will improve with more positive socioemotional exchanges. Positive social emotional exchange to increase parent-child interactions and

improved quality of life (QoL) for the families is one of the main objectives and outcomes of the program.

These theoretical frameworks complement a community-based model with a family-centered practice (FCP) approach and is tailored to the individual needs of each participant, (parent and child), using the different theories to support all learners in this program. The objective of a community-based model is to promote health and prevent illness. FCP is a broader approach that recognizes the important role that parents play in the planning and implementation of a program or intervention. These theories will guide the participants in the WE C.A.R.E. 2 intervention towards positive outcomes in a natural and supportive environment. The models chosen are occupation-focused models with a holistic approach. This would assist caregivers in practicing various techniques to improve mood, gain a sense of competency in their occupation (parent), and create a healthy connection to their child and their community. A community-based program, like WE C.A.R.E. 2, incorporates yoga and mindfulness techniques in the intervention to provide the participants with techniques to manage their stress and their child with ASD. This supports the socioemotional relationship between the caregiver and their child with ASD. This will work to improve family function and bonding and the quality of life for families, by fostering positive parent-child interactions. These techniques will create opportunities for occupational engagement and participation in the families' natural environment , including community and home, to prevent isolation and pro-morbid conditions such as depression and anxiety (Cole & Tufano; 2007; Dunn, 2012).



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Figure 2.1: Explanatory model of the problem

An overview of the problem is presented in the explanatory model (Fig. 2.1) describing the factors e.g. characteristics of autism spectrum disorder (ASD) and poor coping strategies that have an impact on parental stress and the physical, social, and emotional health of the caregiver and their family such as social isolation and anxiety.

Core symptoms and parental stress

Social participation is defined in the Occupational Therapy Practice Framework: Domain and Process as participation that support(s) desired engagement in community and family activities as well as those involving peers and friends (American Occupational Therapy Association, 2014). The child with autism spectrum disorder (ASD) demonstrates persistent deficits in the areas of social-emotional reciprocity, nonverbal communication behaviors used for social interaction, and developing and maintaining relationships (including the parent-child relationship). Research supports the hypothesis that the degree to which a child with ASD exhibits these core symptoms has a significant impact on parental stress (Hall & Graff, 2011; Pastor- Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña, 2016; White, McMorris, Weiss & Lunsky, 2012). Empowerment was a partial mediator for those parents who reported positive gain through empowerment and the child's problem behavior was not related to maternal stress (Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012; Weiss, MacMullin & Lunsky, 2014). For those parents who did not feel a sense of empowerment, their child's problem behaviors were found to be related to parental distress (Weiss, MacMullin & Lunsky, 2014) and caregivers have a tendency to become depressed, anxious, and overwhelmed as a result of dealing with behavioral issues associated with ASD e.g., self-

stimulatory behavior and tantrums (Snow & Donnelly, 2016). This can lead to feelings of isolation and stigmatization for caregivers (Russell & Norwich, 2012). The higher levels of stress that parents of children with disabilities experience the greater the impact on their well-being, which tends to have an effect on the functioning of the whole family, except when gains are made through empowerment. The lack of programs to teach proactive techniques and strategies, that addresses the caregiver and the child's stress associated with problem behaviors e.g., sensory sensitivities and tantrums, along with difficulties in social communication and building attachments, can lead to heightened stress levels and inappropriate and less productive responses. There is a lack of resources, support, and effective community-based programs that can provide support and education for parents on adaptive behaviors and proactive ways to cope with stressful situations when dealing with their child's behaviors (Dunn et al., 2001). The caregiver's environmental stressors have overwhelmed their resources and they have turned to learned and less effective coping strategies to restore family function. Depending on the coping strategies utilized, parents/caregivers can create an opportunity to interact and socialize with their family in a proactive manner that creates positive outcomes with healthy family interaction and relationships, but this may not be the case in some families. There is a tendency to use learned maladaptive ways to deal with stressors, which has had a negative impact on family function with less positive interaction and communication. This can interfere with the parent's sense of competency, confidence, and wellbeing and can lead to mental health issues, without the necessary support and programs to deal with the everyday challenges of raising a child with ASD. Bonis &

Sawin (2016) concluded that adaptation/change can occur throughout the process, but it is in understanding the self-management process that is of the utmost importance to the parents of children with ASD. This allows for the parent to move forward in achieving better health through the gain of insight into different ways to self-manage stress.

There is a need for more evidenced-based interventions (EBIs) that are feasible, flexible, and parent-mediated that can fill the research-to-practice gap (Pickard, Kilgore, & Ingersoll, 2016; National Autism Center, 2009). The complexity and uniqueness of symptoms in children with autism spectrum disorder has made it difficult to pinpoint one specific intervention that meets all the demands and needs of caregivers and their children with autism spectrum disorder (ASD) that works toward the improvement of family quality of life. Several research-based intervention methods for children with ASD have been tested in controlled research settings (Stadnick, 2014; Pickard et al., 2016), but there is little evidence to support the effectiveness of the methods in community-based setting.

Measurement of Stress

The majority of intervention studies examining stress use qualitative data as an outcome measurement for stress in the form of questionnaires such as the Parental Stress Index (PSI). A systematic review by Sharma (2014b) analyzed 17 articles and compared 10 studies and found Cohen's Perceived Stress Scale one of most commonly used to measure perceived stress to determine whether yoga can be an efficacious approach for managing stress. External factors, e.g., range of motion and muscle strength, are easier to

measure than internal factors such as stress and self-efficacy. When examining change in internal factors using parental questionnaires the individual's perspective can lead to a bias and affect the reliability of the test results. When examining yoga as a form of stress management the most common measurement was psychological, though both psychological and physiological have been measured (Sharma, 2014; Sharma & Rush, 2014). Sharma & Rush (2014) conducted a systematic review, including 17 studies and found that 15 out of the 17 studies that measured psychological or physiological changes demonstrated a positive outcome. The commonly used measures for physiological responses are heart rate (and its variability), blood pressure, respiratory rate, as well as salivary cortisol, if possible. For feasibility and practicality purposes during the planning process of a yoga intervention Sharma (2014) suggests most of the interventions range from 6 to 12 weeks to strengthen the reliability of the intervention. Sharma (2014) found that besides Cohen's Perceived Stress Scale, the majority of studies assessed the stress levels of caregivers using physiological measures such as, heart rate, respiratory rate, blood pressure, and other physiological biomarkers.

The advances in technology with socially acceptable, feasible, and transportable devices as a form of neurofeedback (NFT) has made measuring biological variables more mainstream. This increase in mainstream usage of wearable technology that measures and collects data on biological variables could assist children with ASD and their families in detecting the onset of behaviors that may lead to co-morbid conditions e.g., anxiety, depression, and self-injurious behaviors. Wearable devices are one way to provide evidence that an intervention is effective in decreasing stress levels through the

monitoring of cardiovascular activity and measuring heart rate (HR) which measures the number of beats per minute. Recent technology and research on the measurement of physiological biomarkers has provided stronger supporting evidence to clarify the relationship between certain psychological and physiological processes that occur when dealing with stressors (Berntson et al., 1997; Taj-Eldin, Ryan, O'Flynn, & Galvin, 2018; Goessl, 2017; Li, Zhang, Tao, & Ding, 2017). The identification and assessment of different emotional states and physiological changes during the interventions can be monitored and recorded using real-time feedback while making the necessary modifications and adjustments to improve the quality of parent-child interactions and to increase participation and engagement for both the child and the caregiver. An indication of change in the stress levels can be used as a preventive measure when encountering and dealing with stressful situations. The existing barriers have had an impact on the number of existing EBIs and the lack of support to assist practitioners, including occupational therapists, in improving the health and wellbeing of children with ASD and their families. Interventions will need to be carried out in a personalized manner where the caregiver's mental and physical state is factored into the equation during the assessment process and intervention planning. The ability to measure biological variables, such as heart rate, pulse, and temperature change, has improved significantly over the last 10 years. According to Taj-Eldin et al. (2018), a more gold standard measurement used by physiological researchers and clinicians is required to calculate heart rate variability (HRV), providing more accurate information and useful measurement of heart activity. HRV involves the oscillations that lead to variable beat-

to-beat fluctuations in HR that are influenced by everyday performance e.g., physical, emotional, and cognitive (Tyagi. & Cohen, 2016). More accurate information can be calculated using the time intervals R-R (two consecutive resting heart rate peaks) and the measurements of the ECG signal from an ECG sensor on the device (Fitbit Charge wristwatch). The complexity of ASD and the interconnection of multiple symptom areas (e.g., anxiety and hyperactivity) plays a significant role in parental stress levels and their health and wellbeing (Pastor- Cerezuela, et al., 2016; Weiss, J. A., & Lunskey, Y. , 2011). This can also play a major role in the practitioner's motivation to adopt new interventions and implement EBIs that target specific characteristics of each child's behaviors (e.g., anxiety, sensory) to improve the social interaction and communication between the parent and child. The two challenges that community practitioners need to consider with EBIs are factoring in the number of specific targeted areas that will best address the needs of both the child with ASD and the caregiver to improve the quality of life for the family. Other ways to determine the efficacy of a yoga program in stress management are through the design of the program and considering different ways to assess the different dosages (length and duration of each pose, session, and program) and to standardize the intervention with a manual that provides uniformity in the manner in which the program is implemented.

A meta-analysis conducted by Goessl (2017) further supports the findings of other qualitative reviews that suggest the effectiveness of HRV biofeedback as a form of treatment for anxiety. The study yielded an overall effect size of Hedges' $g= 0.83$ in a comparison condition, which indicated that HRV is beneficial in treating people with

anxiety and stress. Just- in -time intervention (JITI) is one example of an intervention that has used a wearable wireless sensing device for health monitoring and the management of stress. In order for this type of device to be beneficial to the client the ability to predict availability is important. The prediction of availability depends on a number of factors such as activity type (i.e., walking), stress, time, location, and day of the week. In a dissertation by Sarker (2016), data from 30 participants was collected and analyzed consisting of 2,064 hours physiological sensors and 2,7171 self-reports. This study points out that in order to detect stress episodes it is important that a time series pattern (multiple readings per session) mining method that collects data in their natural environment is needed to further explore the effects and patterns of stress in real life.

Overall, the quality of life for families of children with ASD will improve with the added elements in place for parents to engage within their communities and manage their child's care in a positive and proactive manner.

Impact of Parent-Child Programs and Yoga on Individuals and Families

Healthy People 2020 emphasizes the importance of health-related quality of life and well-being and has established goals that promote quality of life, healthy development, and health behaviors across all life stages (Office of Disease Prevention and Health promotion, 2016). HealthyPeople2020 relates well-being as a concept of health-related quality of life (HRQOL) and further assesses the positive aspects of a person's life, such as positive emotions and life satisfaction. Well-being is a relative state where one maximizes his or her physical, mental, and social functioning in the context of supportive

environments to live a full, satisfying, and productive life (Office of Disease Control Prevention and Health Promotion). Mindfulness allows time to perceive each situation with greater flexibility, accuracy, and awareness. This provides an individual/caregiver with opportunities to be less reactive and non-judgmental with greater acceptance of whatever is taking place on a somatic, cognitive, affective, or behavioral level (and therefore no longer avoidant) to re-evaluate or reframe the perceived situation. Yoga uses mindfulness to focus on the present moment to connect the breath with the body in a nonjudgmental and kind manner that assists the participant/individual in gaining a greater awareness of their present physiological and physical state. Active engagement in a yoga practice promotes optimal neural regulation of the autonomic nervous system and can actively engage the ventral vagal complex (VVC) (putting on the vagal brake!) through the utilization of specific yoga postures (asanas), breathing techniques, chanting or meditation, which can affect top down (regulation of attention, setting of intention) and bottom up (involving vagal afferents, sensory input related external challenges, and mechanisms that detect and assess environmental risk) (Sullivan, Erb, Schmalzl, Moonaz, Noggle, Taylor & Porges, 2018).

Every 5 years, researchers from the National Center for Complementary and Integrative Health (NCCIH) and the National Center for Health Statistics (NCHS) conducts a National Health Interview Survey (NHIS). The most recent study from 2012 to 2017 showed that yoga and meditation more than doubled and the percentage of children meditating showed close to a tenfold increase for children between the ages of 4 and 17 years of age (NIH, 2019).

Social isolation can be a result of restrictions placed on the family's lifestyle due to the structured routines, which adds to the stress experienced among caregivers when raising a child with ASD. Stress plays an important role in several types of chronic health problems-especially cardiovascular disease, musculoskeletal disorders, and psychological disorders (Centers of Disease Control (CDC), 2019). The CDC recognizes stress management training may rapidly reduce stress symptoms such as anxiety and sleep disturbances (CDC, 2019).

Presently, the two main categories of interventions are behavioral parent training (BPT) and coping skills interventions (CSI) that targets the stress levels of parents with children who have Developmental Disabilities (DD) (Lindo et al., 2016). There is increasing support for ASD treatment that focuses on interventions that work to improve adaptive skills and symptom reduction, parent mediated interventions, and parent training (Vasilopoulou & Nisbet, 2016). These interventions have the potential to optimize situations to use technology to gain more evidence on occupational therapy interventions that teach self-management techniques to improve the quality of life of children with ASD and their families. Self-management techniques can work to improve the quality of the family's functioning and can have a significant impact on the child's cognitive and social functioning and physical and emotional health (Kuhaneck, Madonna, Novak & Pearson, 2015). The quality of the relationship is dependent on the individualized needs and the intervention or program. This type of individualized and client-centered care provides a supportive environment that factors in the bidirectional variables during parent- child interactions to facilitate positive outcomes in the quality of parent-child

relations. As occupational therapists we individualize the interventions by considering all factors (person, environment, occupation) and contexts to keep interventions client-centered through goal setting and planning interventions with the client. An occupational therapist can provide support with many of the commonly reported challenging behaviors and provide an evidenced-based and family centered care (FCC) approach that meets the needs of the caregiver and the family. Kuhaneck (2015) conducted a systematic review to determine the effectiveness of interventions for children with ASD and their parents implemented by occupational therapists. Sixteen out of the thirty-four articles reviewed involved parent-mediated interventions directed at the child, either alone or in combination, with parent training, education, or coaching. Parent training was often aimed at enhancing communication through play, decreasing problem behaviors, and routine setting. Parent groups are an opportunity to share information such as diagnoses and services in a supportive environment.

Other forms of EBI incorporated relaxation techniques for stress management (e.g., mindfulness training, yoga, Stepping Stones Triple-P Positive Parenting Program, TEACCH, and pivotal response training). Two studies that support parent training and the effectiveness of a behavioral family intervention were from Australia (Tellegen & Sanders, 2013). The focus of the training was to reduce aggressive, forceful, and inconsistent parenting skills in order to increase positive parent-child interactions. The quasi-experiment showed that parents reduced their over-reactivity and stress levels, along with improvements in depression and anxiety. Positive behavioral changes in children's disruptive behavior problems were reported by the parents during parent

training. A systematic review and meta-analysis conducted by Tellegen & Sanders (2013) assessed the treatment effect of Stepping Stones Triple-P Positive Parent Program (SSTP) with children who have disabilities. The review and meta-analysis yielded significant effects on parenting styles, parenting satisfaction and efficacy, parental relationship, parental adjustment, and child observations. Child behavior was found to have moderate effects across all levels of intervention using SSTP with parents of children with disabilities. Only one of the studies in this review would be considered effective, and the author is recommending more effective trials to assess the effects of the SSTP program in more natural settings (Tellegen & Sanders, 2013).

Bellefontaine (2013) conducted a meta-analysis using a wide age range of children (toddlerhood to adolescence) to support the use of behavioral parenting interventions for the treatment of disruptive behavior disorders (DBD). In this intervention parents are taught to become agents of change in their children's behavior through the use of techniques based on the principles of Bandura's social learning theory. This study provided evidence that demonstrated how behavioral parent interventions can create a change in the parents' behaviors. Among those behavioral changes were increased use of differential attention, praise, and time-out, and reduced use of spanking (a less proactive approach). Some other positive outcomes from the study by Bellefontaine (2013) were the reduction in child behavior problems such as aggression, acting out, antisocial behavior, and non-compliance; and provided evidence that a correlation exists between behavioral parenting interventions and improvements in parent adjustment such as lowering symptoms of depression, stress, and anxiety, and increasing

marital satisfaction. The moderating factor in parental adjustments was the child's age. This provides evidence that the parent-child interaction is a bidirectional variable where the child's age and parental coaching in a natural setting should be taken into consideration when therapists are working with behavioral changes in caregivers and their children with ASD. Therapists can support parents by providing problem solving strategies that are adapted to their child's functioning and assist in finding parents individuals who can support them, either in their community, organization or through a trained professional to improve their quality of life.

Adapting a yoga intervention for individuals with ASD

There is a growing body of research suggesting that ASD providers can successfully deliver community-based interventions (practices) that are evidenced-based for caregivers and their children with ASD. Interventions that identify and detect the different mediating and/or moderating variables (e.g., stress, environment) through adaptive care use different types of support and techniques that fosters the health and wellbeing of the caregivers and their families.

According to the National Institute of Health, yoga is one of the top 10 complementary health approaches used by more than 13 million adults in the U.S. over the previous year (NCCIH, 2017). Mindfulness across all settings and populations is becoming part of evidenced-based interventions to support caregivers and their children with and without a disability. Mindfulness is a form of meditation based on the Buddhist tradition and has been utilized for over two decades to treat mental illness (Bögels & Restifo, 2014; Sharma & Rush, 2014; and NCCIH, 2017) by focusing on a connection

between the mind, body, and health (Hourston & Atchley, 2017). Overall, the studies show that there has been an increase in mind-body interventions such as mindfulness for children and adults, with and without a disability and supports the use of mind-body therapies in improving mental health in people with ASD (Bögels & Restifo, 2014; Kuhaneck et al., 2015; Sotoodeh et al., 2017; and Hourston & Atchley, 2017). There has been a rapid increase in the interest in mindfulness programs for children to promote self-regulation, self-care and intentional and reflective engagement (Bögels & Restifo, 2014; Kuhaneck et al., 2015; Sotoodeh et al., 2017) with a significant increase noted in the use of yoga from 3.1% to 8.4% and meditation from 0.6% to 5.4% for children ages 4-17 years of age from 2012 to 2017 (National Center of Complementary and Integrative Health, September 26, 2019).

A mindfulness program can have a positive impact on community participation and integration for children and adults with disabilities by incorporating yoga to improve parental self-efficacy and promote social engagement. (Gassaway, Jones, Sweatman, Hong, Anziano, & DeVault, 2017) during an exercise that asks to self-reflect. This would require an intellectual level that would allow an individual the ability to use metacognition to self-reflect on their behavior. Gassaway et al. (2017) supports the use of self-reflection in the learning process and encourages it for the participation in everyday activities and the acquisition of new skills such as stress management techniques for awareness and emotional modulation. Self-reflection assists the caregiver in reframing thoughts and beliefs and allowing the caregiver the opportunity to find meaning and significance in their child's disability. Kuhaneck et al. (2015) defines

reframing as a parent's ability to make the child's disability mean something important for the family and considers reframed perceptions as a possible key to family well-being due to its ability to allow caregivers to adapt and balance the demands of raising the child with other family needs. The management of an individual's internal system (i.e., cognitions, feelings, and physiology), through self-regulation, especial emotional regulation, has an influence on the motivation to learn new concepts and techniques to cope or deal with external factors that may impact functioning, performance, and participation in everyday activities in various contexts, which includes activities within the community.

Adaptations during parent training for positive parent-child interactions

Limitations exist in interventions with evidence-based strategies that address parental stress and social support for families of children with developmental delays (DD) (Lindo et al., 2016) as well as the limitations on the number of community programs for children with ASD (Pickard et al., 2016; Lindo et al., 2016). The limitations are due to a number of barriers such as practitioners adopting to new interventions, training, funding, quality of evidence, and the design and methods of the individual studies that have had an impact on the number of EBIs (Pickard et al., 2016; Lindo et al., 2016; Kuhaneck et al., 2015).

Parent mediated interventions that involve training parents to improve their children's adaptive skills and work toward symptom reduction has gained more support (Vasilopoulou & Nisbet, 2016; Pickard, Kilgore, & Ingersoll, 2016; Kuhaneck et al., 2015). These recent studies have found a positive association between higher levels of

social support and parental quality of life (QoL). In addition, an association was made between health promoting activities such as exercise and healthy lifestyle choices and better perceived mental health among parents. The National Institute for Health and Care Excellence (NICE) (2019), identifies group-based interventions as being cost effective and aligning with their goals of offering evaluations to identify the families and carers needs, including personal, social and emotional support as well as practical support in their role as a parent/carer. The benefit of the implementation of a mindfulness and yoga program in the community is that it addresses the needs and goals of the parent, and indirectly the child's needs. It also offers caregivers, children, and their family's tools to manage their stress and negotiate the effects of stressful situations and trauma as it presents itself in the moment. The findings from the above-mentioned studies support the use of mindfulness parenting programs on providing social and family support, education, and teaching effective coping strategies. The practice of yoga has the ability to improve attention and emotional control, through relaxation techniques, that create a state of homeostasis, in the Central Nervous System (CNS) (Sotoodeh, 2017; Sullivan et al., 2018). A cognitive behavioral approach can apply techniques to assist the parent to manage anxiety or emotions and remove the barriers caused by distorted thinking. A mind-body connection during a parent-child partner yoga intervention, along with the techniques derived from CBT can create the mechanisms of change (coping strategies, stress reduction, psychological homeostasis, efficacy, and positive parent-child interaction and socialization) by incorporating relaxation techniques, such as breathing, meditation, visualization, and a sequence of postures. The principals of yoga and

occupational therapy models focus on behaviors and the strategic use of activity (yoga) to practice adaptive skills and motivate learning (Cole and Tufano, 2008, p. 152) that promotes the health and well-being of the parent, in order, to assist the child's emotional regulation and increase participation. During the participation of a yoga intervention the parent will focus on the learned techniques and reversal activities, such as coping mechanisms and distraction exercises, to increase self-efficacy, improve parent-child social interaction, and promote healthy relations with their child. Other findings found a correlation among various factors, such as resources, the stressful event (disability) and perception of the individual on a certain situation e.g., child's behavior. Other recent studies with stronger evidence supports centered-based programs (Kuhaneck et al., 2015) that creates positive change in personal, social and emotional support as well as practical support in their role as a parent/carer during a mind-body intervention, which may be due to the intensity of the program and the funding to support interventions. Another study by de Bruin, E. I., Blom, R., Smit, F. M., van Steensel, F. J., & Bögels, S. M. (2015), uses a mindful parenting training called Mymind that includes adolescent children with ASD and offers some helpful tools for parents. Mindfulness techniques teach parents to slow down and be less reactive, in order, to demonstrate proactive behaviors that are problem-focused, instead of emotion-focused, while dealing with the stressful and difficult behaviors of their child. Through the use of different breathing patterns and the attention is on awareness of their intention to participate in the moment, which allows for the opportunity to make a more positive choice, with a reduction in reactivity, and one that will benefit the caregiver and the child towards a more healthy and meaningful life.

Higher resting HRV is associated with more adaptive and functional top-down and bottom-up cognitive modulation of emotional stimuli, which may facilitate effective emotion regulation. Conversely, lower resting HRV is associated with hyper-vigilant and maladaptive cognitive responses to emotional stimuli, which may impede emotion regulation (Sullivan, Erb, Schmalzl, Moonaz, Noggle Taylor, & Porges, 2018). Recent studies in a systematic review found that parent-child intervention and the adult with ASD were consistent with one another in regard to rumination and quality of life, but not worry and mindfulness. The qualitative data from the parent surveys determined that a mind-body intervention, such as the Nurtured Heart Approach (NHA), using both mindfulness and yoga further supports the benefits of a mindfulness practice with parent training programs (Brennan, Hektner, Brotherson, and Hanse, 2016). According to Brennan (2016), NHA provides the first parent program with empirical evidence in a community setting (non-clinical) using a mind-body intervention and demonstrates a bidirectional relationship in behavioral change between the parent and the child and the improvements in parent-child engagement and well-being. A large percentage of the parents involved in NHA reported a reduction in ineffective parent-child interactions and an increase in positive practices with increased parent confidence reported on the follow-up at the end of the program. Common themes reported on the parent self-assessment involved a change in the child's behavior and attitude; changes in their children's emotional control and their children's response to positive attention, compliance, and improvement in general disposition; and the child being calmer or less reactive, with a faster recovery from emotional distress. The correlation between positive parent

perceptions of their child and their child's response to positive attention suggested that children were highly responsive to positive attention (i.e. recognition). The recognition techniques were viewed by the parents as a major contributor to the improvements noted in their children's behavior and family interactions i.e., children are more respectful towards one another. This reinforced the development of pro-social behaviors (e.g., team player, helpful to others) and improved confidence or self-esteem, which was considered by the parent to play a big role in the child's compliance and general improvements in attitude or disposition (Brennan, et al., 2016).

Huber et al. (2011) describe mental health as an individual's ability to cope during adversity and bounce back from a strong psychological stressor, in order to prevent post-traumatic stress. In addition, Huber et al. (2011) describe physical health as the maintenance of physiological homeostasis during stressful circumstances/situations to prevent damage and/or illness. A mindful parenting approach is another way to address high parental stress that may have been brought on by the demand(s) exceeding the resources available to the caregiver, and for parents with mental health concerns (psychopathology themselves) (Bögels & Restifo, 2014). A mindful practice such as yoga provides multimodal learning with a combination of breathing, movement, and meditation addressing different aspects of health (e.g., physical, physiological, and psychological) to create homeostasis when feeling highly stressed or faced with a psychological stressor; preventing distress that could lead to illness and co-morbid conditions e.g., anxiety, depression. Preventive options through the use of empirically validated strategies of breathing, postures, and meditation (Brennan et al., 2016; Sullivan

et al., 2018; Sotoodeh et al., 2017) during the participation in a wellness program can provide the quantifiable documentation through the recording of physiological changes and the outcomes. A wellness program that incorporates yoga and mindfulness could provide individuals/ caregivers with resources and tools for coping to strengthen resiliency and empower him/or herself to participate in everyday activities with their child in different contexts (e.g., home and community) to foster emotional and physical wellbeing. Mindfulness techniques assist children and their parents in becoming mindful of their actions and teach them to slow down and be aware of their intention before handling a situation. Mindfulness is a form of meditation based on the Buddhist tradition and involves being present in the moment, focusing on the reality and accepting it for what it is (Bögels, & Restifo, 2014). Modified deep breathing techniques in a mindfulness practice, such as yoga, can be utilized to meet the needs of the individual at each moment (breath) to create a space for teachable moments before responding to a behavior exhibited by the child or adult that may trigger an emotional intense response, thus reducing reactivity (Bögels & Restifo, 2014; Goldberg, 2013). Parental calm is of particular importance for children with ASD since they function best when their social environment is predictable and not on sensory overload.

Although there is limited evidence to support the use of mind-body interventions and the use of relaxation techniques as mechanisms of change for behaviors, there is some evidence with moderate strength to support parent coaching in the home or a center to reduce stress and improve family coping and resiliency (Kuhaneck et al., 2015). Stressors associated with raising a child with ASD include the need to have rigid

or structured routines, which can restrict the family's lifestyle, create social isolation (Bishop, Richler; Davis & Carter, 2008; DeGrace, 2004), and hinder the development of typical family routines. A group-based intervention such as parent training programs that incorporate mind-body practices can provide parents the opportunity to develop relaxation and coping strategies with a network of social support. The lack of social support has been identified as a moderator of negative outcomes for parents of children with autism (Dunn et al., 2001).

Modifications for Children with ASD

Several studies and books are available as a resource for practitioners to assist in the modifications required to individual sessions in a yoga program to support caregivers and their children with ASD. Brennan (2016) reports that a causal role exists between specific behavioral changes (e.g., positive attention) given to a child by the caregiver and an increase in the child's ability to adjust and learn. Brennan (2016) found one RCT study that involved adults with ASD and mindfulness interventions to have significantly positive effects on depression, anxiety, and rumination. This study found that 80% of the parents said that they had found mind-body therapies to be moderately or very helpful for their child. Yoga is considered a multimodal learning for students with disabilities (Koenig, Buckley-Reen, & Garg, 2012). Yoga employs structured, predictable patterns and environments, which have been shown to be essential tools for children with autism (Sotoodeh, Panahibakhsh, Mirdoozandeh, & Ghanizadeh, 2017; Goldberg, 2013). A Yoga Therapy Program (YTP) conducted by Sotoodeh et al. (2017) focused on teaching strategies that paralleled those used in conventional autism-related therapies with children

that used teaching strategies with a specialized and inclusive instructional model. Researchers are also recognizing and focusing on the importance of joint attention in young children with ASD, as reported by the National Autism Center (2009). Joint attention is the act of sharing an experience of an object or event with another person. Schertz, Odom, Baggett, & Sideris, (2013) emphasize the importance of turn-taking (TT) and reciprocal repetitive play that creates opportunity for positive parental attention and increased engagement to provide the child with a greater understanding of shared interest of another person by accommodating the parent's turn. Individual attention is provided to the child by a trained yoga therapist/professional and the parent during a yoga intervention and a chosen object e.g., ball, to maintain interest and can be replaced with various props/objects during the performance of postures to keep the attention of the child. The child with ASD requires an environment that is predictable and not overloaded with changes. Calming techniques e.g., breathing, proves to be important in the everyday functioning of children with ASD (Bögels, & Restifo, 2014; Goldberg, 2013; Betts, & Betts, Stacey 2006). The child is taught a bottom-up approach with different breathing techniques (patterns) e.g., Bee Breath, Lion's Breath and body movements to influence the musculoskeletal, cardiovascular, and nervous system function. Breathing, pose/postures (asanas), and the space can be adapted to meet the needs of the individual through the use of props (e.g., blocks, straps, and tempo of music) and certain adaptations to the environment to provide a conducive space to learn. Relaxation occurs when an individual feels safe (Radhakrishna, 2010; Goldberg, 2013) and is not threatened by their environment. The yoga mats provide each individual with

boundaries and the ability to visually identify their personal space throughout the intervention. The mindful movement (yoga postures) combined with speech and language stimulation increase recall ability, imitation skills, verbal receptive skills, and expression (Raghuram, S., Raghuram N., and Nagendra, H.R., 2011). Yoga can create an environment that is quiet, playful but structured and predictable preventing sensory overload and creating a conducive learning environment that is “just right”. The choice of the postures, duration of the session, and the amount of interaction with others is tailored to meet the individual or child wherever they are at each moment and/or movement (Goldberg, 2013). Variations in postures (i.e., forward bends) and breathing (i.e., longer exhale than inhale) can stimulate the central nervous system to calm or stimulate an over-responsive or under-responsive central nervous system, in order, to elicit positive responses through direct instruction and input (Goldberg, 2013; Radhakrishna, 2010; Sotoodeh et al., 2017). The mindful movement (physical exercises) combined with speech and language stimulation increase recall ability, imitation skills, verbal receptive skills, and expression (Raghuram, S., Raghuram N., and Nagendra, H.R., 2011). Yoga can create an environment that is quiet, playful but structured and predictable preventing sensory overload and provides a conducive learning environment. Systematic changes can be made to the environment e.g., lighting, decrease in visual and auditory stimuli, which would increase the predictability of the routine. These studies provide evidence that higher resting HRV is associated with flexible and adaptive top-down and bottom-up cognitive processing, which facilitates effective emotion regulation, in comparison to lower HRV and hyper-vigilant and maladaptive bottom-up and impaired

top-down cognitive response to emotional stimuli (Sullivan, et al., 2018). The results of these studies raise the possibility that maladaptive cognitive processing of emotional stimuli observed in people with lower HRV may be detrimental to emotional and physical health, which explains why people with a wide range of psychopathologies and health issues exhibit lower HRV.

Goldberg (2013) further suggests that mindfulness techniques may help parents to pay attention to their child in a more open and nonjudgmental way that nurtures acceptance and utilizes a gentler approach when dealing with stressful situations, in order, to create a more positive parent-child relationship. The above-mentioned environmental and instructional modifications can be made to increase participation and increase positive caregiver-child interactions. According to the recent research (Sotoodeh et al., 2017; Sullivan et al., 2018; Bögels, & Restifo, 2014) mindfulness interventions such as yoga can potentially improve attention and bring about change by creating homeostasis (sense of balance) and putting on the brakes during the fight or flight (parasympathetic system more dominant and stabilizing the autonomic nervous system) , in order, to be more reflective, reduce stress, reduce parental preoccupation due parental and/or child mental health issues and increase executive function skills in the parent and the child. This enables the parent and the child to a higher resiliency with a quicker cardiovascular recovery after an emotional experience, thus exhibiting more adaptability and flexibility during stress (Sullivan et al., 2018).

Summary

The community-based WE C.A.R.E. 2 program will incorporate yoga and mindfulness techniques in the intervention to provide the participants with techniques to manage their stress and the behaviors of their child with ASD. This will support the socioemotional relationship between the caregiver and their child fostering a positive and reciprocal relationship. This will work to improve family function and quality of life by fostering positive parent-child interactions with a flexible and supportive environment that adapts and modifies the activities to increase participation. These techniques will create opportunities for occupational engagement and participation in the families' natural environment, including community and home, to prevent isolation and co-morbid conditions such as depression and anxiety (Cole & Tufano; 2007; Dunn, 2012).

There are a limited number of valid and strong evidenced-based interventions that address parental stress. Recent research suggests assessing and addressing family functioning with the focus beyond stress and more on coping and resiliency or even QoL (Kuhaneck et al., 2015). Mind-body interventions are in their infancy and more quantitative studies that use standardized training techniques with a larger number of participants are needed for future research. Recent research recommends parent training as a significant part of an effective intervention for autism (e.g., Lord & McGhee, 2001; Dunn et al., 2001; Smith, Koegel, Koegel, Openden, Fossum, & Bryson, 2010), due to its ability to enhance generalization of skills in the child's natural environment and increasing the carry over skills into daily routines and different contexts. While the advances in technology with socially acceptable and transportable devices, as a form of

neurofeedback therapy (NFT), has made measuring biological variables more mainstream, feasibility is in question. This shows promise for increasing the mainstream usage of wearable technology that can be utilized as a preventive measure in managing behaviors that may lead to co-morbid conditions e.g., anxiety, depression and collecting data on biological variables for children with ASD and their families. The increased adoption of electronic devices and information technologies allows the opportunity to monitor the health and wellbeing of the caregiver as well as the child with ASD as a self-management tool to improve QoL. The qualitative and quantitative evidence varies for the use of mind-body therapies, including biofeedback, guided imagery, meditation, and yoga, for children but the evidence is supportive, and safe. More intensive studies with strong support and more participants, using a combination of qualitative data (e.g., questionnaires) for client-centeredness and quantitative data, using new technology e.g., Fitbit watches, that can be validated against the gold standard (Taj-Eldin, 2018), along with long-term follow-up are necessary. This would strengthen the validity of the interventions and determine the significance and/or effectiveness of various interventions on the health outcomes of the families of children with ASD.

CHAPTER THREE – Description of the Program

The Compassion, Awareness, Respect, and Engagement (WE C.A.R.E. 2) Partner Yoga Program will be established within the community for families and their children with Autism Spectrum Disorder (ASD). This parent-child yoga program will provide support, education, and coping strategies for the target population of caregivers and their children with autism spectrum disorder (ASD) ranging from age five to eight years. This program is designed to improve family functioning through empowerment that increases participation and engagement in different contexts (i.e., community, home), thus improving quality of life. The program begins with a two-hour introductory session for the caregivers that will educate and train them on their child's diagnosis and the components of the program with training included. The introduction session will be followed by eight consecutive one-hour sessions twice a week for the five parent-child dyads. It will provide a safe, supportive, and structured learning environment where caregivers can gain insight into their child's diagnosis, identify ineffective behaviors, gain resources to cope with and manage their stress, and support and guide their child's social and emotional learning. This program will provide a support network that promotes positive coping cognitions (e.g., positive internal dialogue or thoughts about situations) to improve physical and emotional wellbeing for the caregivers and their children. The program will align with the World Health Organization's (WHO) explanation of the different ways to create healthy environments or opportunities to promote health using a prevention strategy that enables people to have increased knowledge and control over their health, requiring an alliance from different agencies

e.g., government, non-government organizations (NGO's). This will create healthy environments or opportunities (World Health Organization, 2009). The expansion of the program into the second year of the dissemination plan will allow more families to participate in this health promotion program and help to prevent distress and decrease the number of mental and physical health co-morbid conditions, i.e., anxiety, depression, among caregivers caring for their children with ASD. The core symptoms (e.g., aggression, impaired social interactions) exhibited by children with ASD has had an effect on the degree of parental stress (Argumedes, Lanovaz, Larivee, 2018; Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez & Navarro-Peña, 2016; White, McMorris, Weiss, Lunskey, 2012). The WE C.A.R.E. 2 program will address the cognitive and physiological responses of the caregiver by changing the way the caregiver thinks and responds to the maladaptive behaviors of their child and the way they will deal with stressful situations themselves. Caregivers will be provided with opportunities to practice stress management techniques and coping strategies through breathing, yoga postures, and meditation in a supportive, fun and engaging manner. Formative and summative evaluations will determine the program's feasibility, readiness, delivery, outcome measurements, and the effectiveness of yoga on parental stress levels and quality of life. This program will also consist of a 1-week intensive training program for the staff prior to the start of the program to provide consistency among facilitators and the efficacy of the program.

Program Design: Yoga, ASD, and coping mechanisms for families

Yoga is recommended to be a lifelong practice for self-management, especially for children with ASD, so that the benefits of using yoga can be incorporated into everyday experiences. This involves both the psychological and physiological elements through breathing techniques, postures (asanas), and the cognitive controls of relaxation and meditation to create a state of homeostasis within their system (Radhakrishna, Nagarathna, & Nagendra, 2010). “Through the use of certain breathing techniques for stress management and a form of coping, the individual(s) will be able to respond to situational triggers in an adaptive manner with more realistic perceptions (thoughts and feelings) about specific situations or circumstances” (Kielhofner, 2009, p. 249). This is consistent with the aim of the program and the ability to use adaptive coping strategies such as breathing to decrease stress levels and work toward more adaptive behaviors to manage those situations that have a tendency to trigger maladaptive behaviors. Studies highlight the inverse correlation between these kinds of cognitive mediations (re-assessing situations) and their effect on stress response and their effects on stress levels (Dunn et al., 2001; Radhakrishna, 2010). The individual is given an opportunity to participate in a non-threatening, non-judgmental, and stress-free manner to maintain a state of homeostasis (relaxation and balance) that is conducive for learning throughout the program. The body’s ability to switch off the stress response during the breath work will assist in emotional regulation and create a safe and positive space to learn and develop skills. When a person associates learning as safe and pleasurable, the brain is focused and more attentive, which helps the person to organize and process information

in a way that makes sense (Goldberg, 2013). Feeling safe is essential for relaxation and for children with ASD, who have difficulty with anxiety and modulating their emotions (Betts & Betts, 2006). The breathing exercises will create a qualitative change that balances the central nervous system (CNS) and creates a state of homeostasis and relaxation (Sotoodeh et al., 2017). The most important effect of yoga is relaxation. A number of different breathing exercises or techniques can be utilized, depending on the needs of the child and their cognitive level.

The WE C.A.R.E. 2 program aims to address the needs (e.g., emotional and physical) of the participants, both caregiver and child, through the use of specific yoga breathing techniques and postures. All stakeholders will be provided with materials that support the efficacy of a parent-child yoga program, which will include an outline of the program, picture cards, demonstrations. For those children with cognitive deficits, a simple breathing exercise of deep breathing, using visual and verbal cuing may be necessary (i.e., smelling the flower and blowing out the candle with counting) to understand the concept of breathing and decrease stress levels. Some additional techniques were found to be effective as a calming agent when working with children who have ASD, such as 4 count inhale/ 8 count exhale, Bee Breath, and Ocean Breath (Betts et al., 2006). The first breathing exercise is one that would require the person to use a longer exhale count than their inhale count (e.g., 4 inhale-exhale 8). The Bee Breath requires the individual to cover their ears and make a humming sound like a bee. The Ocean Breath requires the individual to make a small sound, like the ocean, when inhaling and exhaling from the nose. These different calming breaths create a

physiological change where the breathing rate and heart rate slows down, blood pressure and muscle tension are lowered, and the state of relaxation is maintained (Sotoodeh, et al., 2017). By creating an environment that is conducive for learning (pleasurable and non-threatening), through the use of breathing techniques and the necessary adaptations and/or modifications, the person is able to increase their ability to participate, improve the quality of their performance, and gain meaningful relationships. The intended outcomes have a bidirectional relationship where quantitative changes would improve parent-child relationships and an increase in the number of “just right” bonding experiences that would lead to qualitative changes noted in the parent feeling more competent in their occupation (role) as a caregiver of a child with ASD. This will lead to feelings of competency and being in control during stressful situations and will motivate them to spend more time together that will ultimately improve the functioning of the family. The above-mentioned authors provide relevant and current data to add to this study on complementary and integrative interventions, such as yoga, on the core symptoms of ASD. The aforementioned literature provides a foundation on the relationship between a decrease in the core symptoms of ASD and the positive effects that a yoga program can have on emotional regulation and the severity of core symptoms of ASD. The more recent research validates the need for a yoga program that addresses stress management to adapt to everyday changes in a more adaptive manner that promotes the health and wellbeing of this population (Ashburner et al., 2014; Koenig et al., 2012; Betts & Betts, 2016).

The impact of Yoga on the caregiver

Mindfulness interventions such as yoga can benefit parents as well as their children. Yoga can potentially improve attention and bring about change by creating a sense of balance during the fight or flight response to reduce the physiological responses while stressed or in crisis (parasympathetic system more dominant and stabilizing the autonomic nervous system) (Sotoodeh et al., 2017; Sullivan et al., 2018; Bögels, & Restifo, 2014). This allows the caregiver to be more reflective, reduce stress, reduce parental preoccupation due parental and/or child mental health issues and increase executive function skills in the parent and the child (Bögels, & Restifo, 2014). Reflection in mindful parenting enables the parent and the child to a higher resiliency with a quicker cardiovascular recovery after an emotional experience, thus exhibiting more adaptability and flexibility during stress (Sullivan et al., 2018). The implementation of social skills training in the client's natural context should be considered by occupational therapy practitioners to facilitate the generalization and transfer of social participation skills. The use of appropriate social skills will be modeled by the trainers and be reinforced throughout the program with a multisensory approach to learning. Significant differences in time and frequency were evident among the studies reviewed and those with the most positive results met at least 60 minutes at a time on a regular basis for a total of at least 8 hours. A recommended tool for children with ASD in the management of conduct disorders is a structured, group-based behavioral parenting intervention, between 8 to 12 sessions in length and based on social-learning theory (National Institute for Health and Clinical Excellence, 2006).

A change in social participation and behavior will occur as a result of the program through parental cognitive mediation (e.g., appraisal and coping) that are interrelated and will impact each other. This will assist in decreasing the level of stress the caregiver experiences. The involvement in certain breathing techniques, mindful movement (asanas), and self-reflection the caregiver through meditation will be able to change the way they think about a situation and increase their ability to use effective coping strategies and change the perception of a situation and the impact (magnitude) that a certain challenging event (Dunn et al., 2001; Vernhet et al., 2018) has on their behavior.

Intention of program

The intention of the program is to implement a community-based mental health program for caregivers and their children with higher functioning autism that promotes emotional and physical well-being. The program will create an awareness in the community, train caregivers on coping strategies to manage their stress and their child's stress, and gain support from the community while gaining knowledge and skills during the program. Community-based programs are needed to address the occupation-based needs (e.g., social interactions, parenting skills) by providing access to the support, resources, and tools that are so desperately needed in the community for families who have children with autism. By giving people with disabilities equal access to opportunities to be involved in the community it would promote emotional, social, and physical health and well-being of children and their families. Inclusion is a team effort that requires all members of society (e.g., professionals and different organizations within the community). This collaborative effort builds a mutual partnership that has the same

goal in mind and works toward educating and encouraging one another to work together to find solutions and opportunities for inclusion within our community.

The program will provide a space within the community that is safe and non-judgmental that educates, supports, and provide resources for caregivers of children with autism using a yoga-based approach with various types of input, props, techniques, and modifications to accommodate all learning styles and remain client-centered by meeting the needs of all the participants.

Methods to recruit/identify appropriate service recipients

The recruitment of participants will be determined from a previous survey sent out via email to members of an existing partnership (e.g., Family Service League (FSL), Cornell Cooperative Extension Farm). An introduction letter with details of the program will be sent to the established facility for review and then the administrator of the facility will send information to members of the organization i.e., Cornell Cooperative Extension Farm, via internet to the interested members who filled out the survey. The list of responses will be emailed to the researcher. Five dyads that fit the criteria (e.g., diagnosis, age, and intellectual level) will be chosen by the main facilitator of the program. The recipients will be caregivers and children with autism who are between the ages of 5 and 8 years of age with an IQ 80 or greater. A review of participants records from the chosen organization to further identify the dyads that fit the criteria (e.g., IQ, age) and ensure the validity of the program.

The recipients will be contacted via phone by the occupational therapy students to set up a meeting. A short meeting (20 minutes) for the caregivers will be scheduled prior

to the start of the program to collect pertinent information (e.g., consent forms, pre-assessments) and a mini needs assessment will be administered to determine the needs of the participants and their purpose for participating in the group. This will help to determine the effectiveness of the program.

Basis (feasibility, relevance, and scientific soundness)

A recent systematic review of the existing literature on mind-body therapies found yoga to be generally safe and feasible for children and adults with ASD (Hourston & Atchley, 2017). Implementing a yoga program with activities that are fun and engaging does not require expensive materials (e.g., fantasy games, music), just a good imagination, multisensory approach with various forms of input e.g., visual, auditory, and proprioceptive cueing, and yoga mats for boundary setting.

Funding for the materials/equipment for play and/or sensory input and attention (e.g., balls, cue cards, music) can be purchased through mutual partnerships with research universities, or seek donations and apply for small grants to assist with the costs through a local autism organization and other profit and non-profit organizations within the community invested in the same cause and mission. This program will be part of a fieldwork and/or research project for the occupational therapy students attending universities within the surrounding communities. The utilization of occupational therapy students during fieldwork experience will make the program more feasible and cut costs for staffing, along with assisting the effectiveness and sustainability of the program. Therefore, the students will be trained on the various techniques and movements in the WE C.A.R.E 2 Program for one week (35 hours) prior to the start of

the program. The training will allow the facilitators (OT students) to apply yoga concepts and their components to the intervention, as a therapeutic tool, when licensed as an occupational therapist. These training hours can count toward a 200-hour certification as a yoga instructor. A manual with supportive materials will be provided to the caregivers and staff (students) to provide information (written and visual) on various breathing techniques and postures to assist in the validity and reliability of the program. The program director will be instructing and training students, so this will not be a cost to the program. Other professionals within the existing organizations or agencies will assist throughout the program by collecting data, recording information on the computer, and providing the “just right” opportunity through demonstration both verbal and manual prompting.

A multisensory or multimodal approach (e.g., tactile, auditory, visual, and vestibular) will be designed to match the needs of the participant by being responsive to and minimizing behavioral signs that are indicative of stress (e.g., crying, screaming) to support proactive behaviors. This will support the quality of caregiver-child interactions and participation (e.g., degree and duration of participation). This will encourage more reciprocal interactions between the child and caregiver (i.e., more back-and-forth exchanges, and following each other’s rhythms), while engaged in parent-child yoga. Pre-mid-post testing, to collect quantitative data throughout each session, will take place to determine the effectiveness of the program and to make the necessary changes to the program. Qualitative data will be collected before and after the start of the program. The efficiency and consistency during the data collection will be ensured throughout the

program by the lead facilitator (main researcher) and will oversee the following steps: trained individuals will collect and record the various data, both qualitative and quantitative, from the all five evaluations e.g., fidelity checklist and heart rate from Fitbit watch; and provide storage tables with relational database to organize variables that has been compiled on a computer (e.g., forms online). This will provide visual data on any existing relationships between the variables e.g., stress levels and self-efficacy and competency as well as a comparison between perceived and real-time stress levels experienced by the caregiver. A video of the dyad interactions will be used pre-post intervention to compare to the checklist and caregiver self-evaluation.

A PSI-SF and Brief COPE will be sent via email to the caregivers prior to the interview. The information will be processed into a main computer by a separate trained volunteer (other than interviewer) directly after the completion. The director of the program will analyze the data collected from the PSI and Brief COPE to understand the baseline data of the different dependent variables i.e., stress levels, symptom severity, and coping strategies. The baseline data will be compared to the data from the post tests for a correlational analysis. This will determine the strength and direction of any relationships between the independent (WE C.A.R.E. 2 program) and dependent variables e.g., stress, coping strategies, self-efficacy, and competency. The records will be stored in a locked room at the facility. Prior to the start of the program, the collection of medical records from the non-profit organization (confirming diagnosis and severity of symptoms). These assessments will be administered at the site by the director (me) and other professionals trained in administering tests, during the interview or emailed before

the start of program. Observations will take place during each session and be recorded every day by the same trained volunteer (one per parent-child dyad). The researcher will recruit occupational therapy students (OTS and OTA's) from local universities as trained volunteers/facilitators for parent-child modeling of postures and behavior management and trained observers for data collection on behaviors/parent-child interactions. This will assist with the feasibility of the program.

The data entry (baseline of stress levels) from wearable devices (Fitbit charge 3) will be tested on the first day of the program to ensure the accuracy and efficiency of the readings and functionality of the equipment. The rest of the assessments will be administered on the first day of the program (Canadian Occupational Performance Measure - COPM) and Sensory Profile (SP).

Relevant policy and systems information in its design

Capacity building will occur through community building in a pre-existing community non-profit organization. The community will be strengthened with the newly developed health promotion to prevent any health issues of caregivers due to high levels of stress while raising children with autism. The contemporary cognitive behavioral theory principles and techniques can be useful in assisting the caregiver and their child with ASD to manage anxiety or emotions and remove the barriers caused by distorted thinking. A mind-body connection during a parent-child partner yoga intervention, along with the techniques derived from cognitive social theory can create the mechanisms of change (coping strategies, stress reduction, psychological homeostasis, efficacy, and positive parent-child interaction and socialization) by incorporating stress management

techniques, such as breathing, meditation, visualization, and a sequence of postures. The principles of yoga and occupational therapy models focus on behaviors and the strategic use of activity (yoga) to practice adaptive skills and motivate learning (Cole and Tufano, 2008) that promotes the health and well-being of the parent and the child. The cognitive social theoretical framework proposes that through participation in a yoga intervention the parent will focus on the learned techniques and reversal activities, such as coping mechanisms and distraction exercises, to increase self-efficacy, improve parent-child social interaction, and promote healthy relations with their child.

This community is considered a functional community because it is a group of people that are connected with shared elements e.g., occupation, in a specific location. This functional community program will align with two of the major goals set by the U.S. Department of Health and Human Services' *Healthy People 2020*. Among those goals that the WE C.A.R.E. 2 program will address are creating a social and physical environment that promotes good health for all and promoting quality of life, healthy development, and healthy behaviors across all life spans (Office of Disease Prevention and Health Promotion, 2016).

Process of delivery/activities of program

A nine- week yoga program will be delivered twice a week for one hour, with the exception of a two-hour informational caregiver session on the first week (1/week), at an established facility in the community. An introductory session will take place on the first session and will familiarize the caregivers to the program, complete any necessary paperwork, baseline evaluations, and provide support and share concerns and ideas with

other caregivers. The yoga sessions will be directed by an expert trainer that is registered yoga therapist, who is an occupational therapist with 25+ years of experience working with children and familiar with autism. Adult models/facilitators will be graduate occupational therapy students from area universities completing their level I and II fieldwork. The facilitators will be responsible for modeling the components of the program, such as breathing and postures, as well as assisting the expert trainer in delivering the sessions. The models will have forty hours of training a week prior to the intervention with individual instruction on the techniques for the program and each model will have a manual and video to refer to throughout the program. During the introduction the caregivers will receive resources and practice techniques, e.g., a manual and demonstrations of various components of the programs to refer to after the completion of the program. The environment will be least restrictive by clearing the room and decrease the number of distractions (e.g., less furniture, low lighting, relaxing background music, and away from other high traffic areas) to provide a non-judgmental and calm experience. Yoga mats will be provided for each participant for their personal space and boundaries. The structure of the 60 -minute session will be modeled after a standardized yoga session, as described in the manual with supportive materials. This resource will include creative activities and visual cues that are proven to motivate, create meaning, and increase participation among this population (Bersma, D & Visscher, M., 2003; Goldberg, 2013; Kaur). One of the main ingredients in this intervention is the caregiver as the agent of change and their ability to facilitate joint attention and/or reduce maladaptive behaviors and assist their child in using self-regulatory techniques. The caregiver will be actively

engaged in moderating change within themselves and their child by creating the appropriate environment or “just-right experience” that determines the effectiveness and strength of a complementary therapy/intervention, such as yoga, on the severity of the core symptoms of ASD.

The yoga curriculum will be organized to address both the stress levels of the caregiver and the developmental level for the child. Various tools will be utilized to assist the dyads (caregiver and child) to transition through the different phases and changes throughout the program. A total of three different breathing techniques and various yoga poses from the manual will be utilized during the intervention with various sequences, based on the individual needs and abilities. Each session will follow the same sequence throughout the program, which will consist of 10-to 15-minute introduction (e.g., name and share about the day) with a game and song. A different child each week will pick one new movement card from a choice of 4 asanas. Then, 5 to 10-minutes of breathing warm-up with one new technique added every three weeks; 20-minute dyad movement sequence; 5-minute relaxation/transition; 10 to 15-minute creative art expression e.g., journaling drawing, poetry; and 5 minutes of sharing experience/creative project. The movements will consist of postures that are based on the basic principles of *Hatha* (physical) yoga (Betts & Betts, 2016). The movements consisting of an opening seated meditation with breathing exercises, warm-up and centering poses, standing poses, balance poses, cool down/ spinal twists, and final resting pose. The description of the poses, relaxation imagery, and music will provide consistency and mood using language and wording that will be understood by all learners, such as one or two word descriptions

with cueing, visually and auditorily. The poses were presented in English, not Sanskrit. The session will be presented in a noncompetitive and fun manner to decrease stress and increase motivation and participation. An individualized program will be tailored to the individual needs by having the instructor (facilitator) encourage the dyads to participate based on where they are at each moment to moment (breath and movement). One way that an individualized plan will occur is through specific breathing techniques and movements that will be chosen to create the mechanisms of change (behavior, cognition, and sensory modulation) among the children and adults in the yoga group. The professional collaboration of different disciplines (occupational therapy, yoga therapist and teacher) will provide the appropriate modifications to the environment and provide the necessary input for the “just right” experience for a positive outcome.

This community-based program works to decrease social injustice by allowing opportunities for caregivers and their children with ASD to participate in activities to encourage positive social exchanges (interactions) and gain a support network that empowers and increases emotional well-being.

Potential Barriers and Challenges:

The need for specialized training in children with disabilities, including autism-related interventions for families has been a barrier to effective implementation and sustainment of other programs in the literature (Todd, Bromley, Ioannou, Harrison, Mellor, Taylor, & Crabtree, 2010). Trained professionals in yoga and mindfulness interventions/programs can educate parents and staff members on the benefits of the program and it’s the components through professional development programs and

consultative services held by the district or in partnership with local agencies, parent advocacy groups, or research universities that provide workshops , in-services programs , and other educational seminars. A potential strategy for a greater success rate of the implementation and sustainment of the program will be in building internal capacity and support, e.g., training administrator, special education liaison, using the train-the-trainer models. Train-the-trainer models will work best with this program, since this has been the most successful when used to train supervisors in community mental health agencies (Southam- Gerow et al., 2014). A modified manual with support materials will be utilized from previous programs that will ensure the reliability of the program (Betts, Betts, & Stacey, 2006; Kaur, Bhat, Getchell, Lobo, & Pescatello, 2016). I chose to conduct the program in the afternoon to employ structured, predictable movements and environment to increase engagement and interaction with partners while involved in yoga activities. These structured and predictable patterns, using repetition, will assist children with ASD to feel calmer and more awake (Radhakrishna, 2010). This will provide a conducive environment with the appropriate tools that promotes proactive behaviors. The first session will be an informative session for the caregivers that will provide the details of the program to become familiar with techniques and the program. The appropriate placement of wearable technology will be practiced by the assistants (OT students) during the first session to ensure the reliability of the information recorded.

Funds could be a potential barrier for materials/equipment, and staff, especially for non-profit organizations. Fortunately, social engagement groups are relatively low cost due to the requirement for few resources for successful implementation. (Locke,

Olsen, Wideman, Downey, Kretzmann, Kasari, & Mandell, 2015). This social engagement intervention with a mindfulness and yoga approach, uses a step-by-step guide that is designed to fit within different contexts and different existing infrastructures, keeping the resources and needed materials to a minimal. A potential limitation that could have a significant impact on results is the lack of a control group and the small sample size used for this intervention. These two factors may not provide enough support and evidence to determine the effectiveness of this yoga program on decreasing caregiver stress levels and its impact on family relationships and overall well-being. This pilot program will need more studies to further support the use of yoga and mindfulness programs with these targeted individuals (caregivers) and population (children with ASD). Exclusion factors e.g., age, IQ levels could contribute to null effects. If the inclusion criteria were broadened (e.g., wider age range and non) it would allow for more children with a lower IQ and a larger age range to engage in this practice (NIH, 2018). Children who are non-verbal were excluded from the study. The location of the study will take place in the same town as the participants (within a 20-minute radius of the site). Parents will provide transportation. Not all of the facilities considered for this program are handicap accessible, so children with wheelchairs or walkers will need to be excluded from participating in the study. The program will need to exclude participants who have severe handicapping conditions that will limit their ability to perform the physical demands of the program. Participants will receive a \$30 gift card after the completion of the program to ensure that all participants remain in the program. Validity refers to whether an instrument measures what it is intended to

measure (Kielhofner, 2006, p.29). The device (e.g., Fitbit) is a valid instrument to detect stress levels through the use of heart rate monitoring considered patient-generated data (PGD) (Ng, A., Reddy, M., Zalta, A., & Schueller, S., 2018). Reliability is considered a given instrument that provides stable information across different circumstances (Kielhofner, 2006, p.30). The correct placement and fit of the Fitbit watch is important in collecting accurate data. Regarding physical health conditions have shown that self-tracking i.e., Fitbit can help to motivate positive behavior changes, identify patterns in health and behavior and promote self-management practices for health and wellbeing. The training provided before the program will ensure that all the Fitbit watches are working and accurate in the readings across all participants. Reliability and validity of the PSI- SF supports that parenting stress is a measure that is useful across diverse populations, including Hispanic, poor rural and inner-city parents.

Conclusion

This pilot program will lay the groundwork for the extension of the program and any issues or problems will be addressed for the sustainability of the WE C.A.R.E. 2 program. The Occupational Therapy Practice Framework: Domain and Process 3rd ed. (AOTA, 2014) focuses on routines and the importance of family-centered care. The WE C.A.R.E. 2 program is centered around the needs of the family in relation to managing stress and focuses on daily routines during social engagement in the community (Kuhaneck, Madonna, Novak, & Pearson, 2015). Social participation is defined in the Occupational Therapy Practice Framework: Domaine and Process 3rd ed. ; (AOTA, 2014)

as a participation that support(s) desired engagement in community and family activities as well as involving peers and family. This community-based program will provide more evidence to fill the gap that exists in the literature by strengthening the support for family-centered care with various components of the program (e.g., evaluations, specialized training to specialize facilitators, therapists, and parents). This will work toward the sustainability of a health promotion program that promotes positive parenting practices and the health and QoL for caregivers and their families, with a focus on routine. The participation in a community-based family-center care program such as WE C.A.R.E. 2, using a multimodal teaching approach, will address learners with different needs to increase positive engagement and improve the quality of life for caregivers and their children, using the Universal Design of Learning theory. This community-based program will use a framework that works to empower families and provide social justice and equality for caregivers and their children with autism the community through engagement in occupations, the opportunity to use a support network, and the space and time to use problem-focused strategies for the self-regulation of emotions, moods, and attitudes with their child that fosters positive family relations and emotional wellbeing.

CHAPTER FOUR – Evaluation Plan

Context for the Project

This program was developed as a result of recognized gaps in community-based programs that support families of children with disabilities, especially autism spectrum disorder (ASD). There is a lack of knowledge and funding in existing organizations (non-governmental organizations (NGO's) and governmental agencies) that threatens the sustainability of inclusive, community-based programs. The Compassion, Awareness, Respect, and Engagement (WE C.A.R.E. 2) Partner Yoga Program can fill this gap and increase the number of programs that provide an affordable, supportive, and inclusive environment within the community. This can be addressed through the expertise of occupational therapists who have knowledge and ability to provide the necessary support, education, and practice for the longevity of skill development. Occupational therapists have the knowledge and experience with this population in order to address the individual needs through adaptations and modification within their natural environment, which allows for a more client-centered and occupation-based intervention.

The WE C.A.R.E. 2 nine-week yoga program will promote the health and wellbeing of caregivers and their children with ASD by providing education, support, and tools that will aim to change the cognitive and physiological responses of the caregivers and their children to manage challenging behaviors. The components of the program will assist caregivers in decreasing their stress levels to gain control over every day stressful situations. This will work toward a greater sense of self-efficacy and competency in their ability to handle situations and behaviors that arise, by providing the

strategies and tools to manage behaviors in a more proactive manner. These tools and strategies will work towards decreasing stress levels in the caregiver that will increase their self-efficacy and sense of competency, using a strength-based intervention (e.g., interviewing, goal setting), that is individualized and assists in motivating toward behavior change in their role (occupation) as a caregiver.

The majority of existing research that assesses parental stress is conducted from a qualitative framework and it affects the reliability of data collected (Kuhaneck, Madonna, Novak, & Pearson, 2015; Vernhet, 2018). In contrast, the efficacy of this program will be determined by the evidence collected throughout the program, using pre- post- tests that are qualitative and quantitative in nature. There will be a total of five assessments with qualitative and quantitative data to determine. Among those pre- post tests administered that will include qualitative data will involve scales: perceived stress scale-short form (PSI-SF), Brief Coping Orientation to Problems Experienced (Brief-COPE), a questionnaire (e.g., Parenting Sense of Competence (PSOC), an interview with the caregiver, using Canadian Occupational Performance Measure (COPM), and a Sensory Profile (SP) to focus on the needs of the participants (caregiver, child) in the program.

The quantitative variables will include real-time data that will monitor heart rate variability throughout the intervention using the Fitbit Charge wearable devices (Fitbit, Inc., 2019) on a daily basis that will provide repeated measures e.g., data will be collected at three different time points, using a Fidelity Checklist and videotaping sessions (refer to appendix 2). This will provide quantitative data, using repeated measures at baseline and at the end of the program to determine whether the program had

an effect on stress levels, thus impacting other variables e.g., quantity and quality of parent-child interactions and joint attention, eye contact, smiles. This will help to provide a more reliable intervention that will determine the effectiveness and sustainability of the program and support the extension of the program and service more families (five to ten).

Logic Model

Appendix D is a logic model that depicts the visual representation of the program and the reasoning behind the program's evaluation plan. This theoretically based program will support the mission of the program and convey to the stakeholders the role that occupational therapists play in providing health promotion programs in the community that support, educate, and provide strategies and tools for the health and well-being of families who have children with disabilities, such as ASD.

Scope of Evaluation

The first year of the program, five dyads (e.g., caregiver, child) will participate in a pilot program. The caregivers and their children with High Functioning Autism (HFA) ages 5-8 will participate in a partner yoga program for nine consecutive weeks, twice a week, for sixty minutes at a local nonprofit organization on Long Island, New York. Prior to the start of the program, administrative records will be reviewed to confirm the diagnosis of ASD and the severity of symptoms, along with having the caregivers complete three assessments, consisting of two questionnaires and a scale (e.g., PSOC, Brief COPE, PSI-SF). The first day of the program caregivers will be interviewed, using the COPM and the Sensory Profile, by trained occupational therapy students. This

will assist in keeping the program client-centered and tailoring the program to the strengths, challenges, and needs of the participants. Two goals will be identified by each caregiver and written on the bottom of the COPM by the interviewer. These individualized goals will help to tailor the sessions to meet the needs of each caregiver and allow them to see the change in behavior, by the end of the program. The interviewer will coach each parent toward attainable and measurable goals. This pilot program will include children with HFA between the ages of 5- 8 years with an IQ > 85 and are verbal. Children who are non-verbal will be excluded for the first year of the pilot program but will be considered for the second year of the program. The location of the study will take place in the same town as the participants (within a 20 -minute radius of the site). Parents will provide transportation. The facility is not handicap accessible, so children with wheelchairs or walkers were excluded from participating in the study. The program excludes participants who have severe handicapping conditions that limit their ability to perform the physical demands of the program. Participants will receive a \$30 gift card after the completion of the program.

Evaluation Methodology

Phase 1: Preliminary Formative Evaluation

Phase 1 will occur one week prior to the start of the program. It will involve the recruitment and training of those individuals involved in carrying out the components of the program e.g., occupational therapy students. These students (facilitators) will have the knowledge from the training and their schooling on the targeted population. An experienced and licensed occupational therapist will be assigned to perform some of the

different responsibilities and will oversee the trained facilitators during the evaluation process and throughout the program e.g., assessment, data collection/recording, trained observers, trained assistants, and facilitators for the dyads throughout the intervention. One student will read and record the HR readings on the Fitbit throughout each session (pre-mid-post testing) and another student will be recording data e.g., child's proactive behaviors, number of movements completed together on a checklist. Those students taking the readings and inputting data i.e., heart rate variability (HRV), and interactions, into the computer after each session will be unfamiliar with the purpose of the study to reduce potential bias and to ensure the reliability of the program. A research assistant from the occupational therapy program at the university will be assigned to read and record all the data both HR and interactions into an excel sheet on a computer that is secured in a locked room.

Phase 2: Evaluation Throughout the Program

The summative evaluations will consist of the collection of qualitative data (questionnaires and observations) that will be assessing the effectiveness of the program. The pre-post comparison tests will assist in determining the changes that occur in stress levels throughout the program as a result of the program participation of parents of children with ASD. The evaluation process will consist of five evaluations: the Parent Stress Index- Short-Form (PSI- SF), Brief Coping Orientation to Problems Experienced (Brief COPE), Parental Sense of Competency (PSOC), Canadian Occupational Performance Measure (COPM), and Dunn's Sensory Profile-2.

Parenting Stress Index-Short Form

PSI-SF is a questionnaire that will be administered prior to and after the program (Abidin, 1995). The PSI-SF is a standardized assessment that is a 28-item self-report that measures the participants' responses to life events using a 5-point Likert scale. Parent subscales include Competence, Isolation, Attachment, Health, Role Restriction, Spouse/Parenting Partner Relationship. This assessment will help to gain a better understanding of the amount of stress that the parent experiences when raising a child with ASD and then compare the data from the pre-post tests to determine if the participation in a parent-child yoga program is a mechanism of change in parental stress. The PSI-SF questionnaire evaluates parental stress in two domains: the Child Domain and the Parent Domain. The Child Domain refers to the stress stemming from caring for the child and the challenging characteristics of the child that make raising him or her more difficult. The Parent Domain refers to parental stress relating to their own characteristics and functioning, which may create barriers to their performance as a parent (Derguy et al., 2016).

The Brief Coping Orientation to Problems Experienced

Brief COPE, is a 28-item self-report that measures the frequency of parents use of particular coping strategies during stressful situations (Carver, 1997). The questionnaire has open-ended questions that will help to gain the perspective of the participants (caregivers) such as views on different situations, forms of social support, and planning (i.e., the use of problem-focused strategies). The different categories identified in caregivers during administration of the Brief COPE are either emotion

focused and include acceptance, emotional social support, humor, positive reframing, and religion. On the other hand, there are problem-focused strategies identified, which include active coping, instrumental support, and planning. Finally, behavioral disengagement, denial, self-distraction, self-blaming, and substance use and venting are considered as dysfunctional coping strategies. The results from the pretest-posttest will help in determining the program's effectiveness in the caregiver's utilization of various coping strategies, problem-focused (proactive) and/or emotion-focused (reactive) during social interactions and other life situations with their child with ASD in natural settings e.g., community and home.

Parenting Sense of Competency

PSOC, is a 17-item self-report scale that measures and assesses parent self-efficacy, consisting of two subscales: skill knowledge and value competence subscales developed by Gibaud-Wallston & Wandersman, (1978) and revised by Johnston and Marsh (1989). It contains 16 items that are scored on a six-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. This identifies two principal factors, a measure of parenting satisfaction (PSOC-S), defined as the person's liking of the parenting role and parenting efficacy (PSOC-E), defined as the person's perceived competence in the parenting role. The Parenting Sense of Competency efficacy scale examines the problem-solving and capability of the caregiver to adjust their thinking and tactic (plan) during a stressful situation and feel satisfied.

The Canadian Occupational Performance Measure

COPM is a semi structured interview that is designed to assess clients' perception

of their occupational performance and satisfaction. This is an individualized measure that uses a client-centered philosophy, where the client identifies different areas of difficulty, which includes areas of self-care, productivity, and leisure (Law, 2014). Each item is identified by the client on a scale of 1 to 10 (1 = with great difficulty or not satisfied, 10 = with no difficulties or completely satisfied). The client identifies five most important issues of the perceived level of performance and satisfaction with their performance. Each client will rate their performance and satisfaction on the five identified issues on the post-test. A change in the client's occupational performance and satisfaction within those areas will be determined by subtracting the pre and post scores.

The Sensory Profile-2

SP-2, is a questionnaire consisting of 125 questions related to the child's sensory experiences, using a 5-point Likert scale. The SP is scored based on four areas of processing: seeking, avoiding, sensitivity, and registration and six sensory areas: auditory, visual, proprioception, vestibular, tactile, and oral.

The data collected from the PSI-SF, PSOC, Brief Cope, COPM, and Sensory Profile will benefit other stakeholders (i.e., parents, children, healthcare providers) for future evidence-based interventions and programs that use yoga as a tool for coping strategies, stress management, and/or self-regulation strategies. Occupational therapists, social workers, and other health care providers can benefit from the results obtained from this study. The evidence collected that includes the positive outcomes and/or positive gains (meaning) obtained from the key elements will provide the needed data to support a program that can improve family function, participation in family routines, and family

engagement. The results from these assessments will provide evidence for the necessary financial support from other organizations (non-profit and profit) that will sustain the second year of the program as well as provide more intense program (more length and participants). The evidence can be presented to other organizations (e.g., New York Occupational Therapy Association, American Occupational Therapy Association, Autism Speaks, GAPH, International Association of Yoga Therapists) as well as presented to policymakers, so that these programs can be implemented as an effective intervention and gain more funding beyond the two-year dissertation program. This program will promote positive family relations and improve the health and well-being of children with autism and their families by providing the support, resources, and practice to decrease stress levels and improve resiliency and competency when dealing with dealing with challenging situations. The continued support e.g., financial, manpower from stakeholders (e.g., local universities, families of children with ASD, nonprofit and for-profit organization) will be able to provide more inclusive opportunities to more families that will help to prevent comorbid conditions, i.e., anxiety, depression, due to the effects of stress when handling everyday stressors such as parenting a child with social and sensory challenges.

Evaluability Assessment

The approach that I would take to negotiate with stakeholders is to provide existing research with qualitative and quantitative evaluations using programs similar to this program. This would support and provide evidence on the effectiveness of a yoga program and its impact on decreasing parental stress levels and improving the

quality of life and the intended users (parents and children with ASD). One example would be presenting research by Kaur, Bhat, Getchell, Lobo & Pescatello (2016) on a creative yoga class that examines the effects of an eight-week yoga intervention on the motor and imitation skills of children with ASD between the ages of 5 and eight years old. This could be presented to educational professionals at local universities with occupational therapy programs during staff meetings, present the information on the WE C.A.R.E. 2 program as a guest lecturer on emerging practice to educate the students and spark an interest in this mental health fieldwork. Presentations can be offered to local and national organizations, such as NYSOTA, AOTA, Family Service League (FSL), and Autism Speaks, who have a shared interest and are aligned with larger organizations on a more global level (e.g., World Health Organization, World Federation of Occupational Therapists). The data collection from the evaluations can be shared with major stakeholders mentioned above as well as the facility administrators to continue and/or extend the program. This will provide more strength, support, and sustainability for future evidenced-based programs/interventions like the parent-child yoga program.

Core Purpose

The core purpose of these evaluations is both causative and descriptive. The analysis from the pre-posttests of the PSI-SF will be compared with the data from the administrative records collected on each child's severity of core symptoms. This will determine whether a relationship exists between core symptoms of ASD and the levels of stress experienced by parents when handling difficult situations. The PSI will also isolate which areas are the most concerning and which factors play a role in having an effect on

stress levels while engaged in parent-child yoga. The Brief COPE will determine what coping mechanisms are being used and whether an increase in the use of positive coping strategies (proactive behaviors) were utilized during and after the program. The post tests will serve as both summative and formative measures by determining whether the learned coping skills assisted in events outside of the program to promote positive family relations and healthy outcomes. This will provide summative data for stakeholders and formative data to assess the effectiveness and make the necessary improvements. This will help with the efficacy of the WE C.A.R.E. 2 yoga program on decreasing the stress levels of caregivers to improve the wellbeing and quality of life for families of children with ASD.

Type of Research Design

Six evaluation designs have been chosen with mixed methods that include both summative and formative measures. The summative evaluation will consist of qualitative data (e.g., administrative records, observations, questionnaires with pretest-posttest, interview) to determine the changes in stress levels during the participation in a parent-child yoga program. The sample size will be small (ten participants). The baseline scores collected from data on all six pretest assessments that will help with the validity of my program. The qualitative data will be coded into quantitative data (numbers) to determine the effectiveness of this program and for future research.

The parent- child yoga group will assess parental stress levels and core symptoms to determine whether there are any relationships between the different mediating factors e.g., support from trained facilitators and other participants and empowerment through

increased self-efficacy, using formative and summative designs. This will assist in determining whether any relationships may exist between the different variables. The summative information will be assessed as a formative assessment after the program completion and will be used to determine the effectiveness of the program and if any changes need to be made to improve the program outcomes.

Data Management Plan

To ensure the efficiency and consistency during the data collection the program director will oversee the following steps:

1. Data flow sheet will be used to collect data with updated technology that has a backup server that is linked to each trained observer's computer.

2. Coding for both qualitative (e.g., observation notes/checklists) and quantitative data (e.g., heart rate variability) converted once in data base for accurate time intervals. One type of coding will be interval with standardized questionnaire (PSI-SF and Brief COPE).

3. Table storage with relational database to organize variables; data is compiled on a handheld computer using forms online.

Procedures for data entry: The PSI-SF, Brief COPE, and PSOC will be emailed to the caregivers prior to and on the last day of the program. The COPM and Sensory Profile (SP- parent and teacher forms) will be administered on the first day of the program. The information will be processed into a main computer by a separate trained volunteer (other than interviewer) directly the first three evaluations after receiving via email or email and

completing the last two on the first day of the program. Director/interviewer will use an explanatory method to analyze the qualitative data collected, using the PSI, Brief COPE, and the COPM(Law, 2014). The SP-2 will be used to determine any relationships that may or may not exist between certain variables i.e., stress levels and symptom severity and learned coping strategies; parenting competency/self-efficacy and achieving goals; and improved parent/child relations and quality of life and decreased stress with the consistency in the use of coping strategies and self-regulation tools. The records will be stored in a locked room at the clinic (program site). The observations will take place during each session and be recorded every day by the same trained volunteer (one per parent-child dyad). The researcher will recruit occupational therapy students from a local university as trained observers and mentors/aides for parent-child modeling of postures and behaviors. This will assist in the feasibility of the program.

Plan for data analysis

A visual inspection of data from both graphs (HR) for all ten participants will determine if a change in levels between phase A and phase B has occurred with both variables. Is there an increase in the participant's average HR immediately followed by a decrease in HRV after the participation in phase B? Is there a change in the number of engagements (e.g., smiles, movements) in phase B? Trained observers, including the program coordinator, will oversee the internal consistency of the program and take note of whether the participants (caregivers) were able to maintain a normal resting HR (80-100 or 60 for athletes) throughout the phase B, indicating a possible decrease in stress levels through the detection of heart rate variability (HRV). This will help to determine

whether the participant is in the relaxation response and in a state of homeostasis e.g., balance. Upon visual analysis of the dependent variables (e.g., HRV and number of interactions) the trained observers will inspect the data points to see the changes in the number of interactions and HRV. A change in levels between the final data point for phase A and first data point for phase B will indicate a change in the quality of parent-child engagement. A visual inspection for an increase from the first data point to the last to determine a trend in phase A and phase B would be indicative of a positive slope (correlation) from the beginning to the end of phase B. It is also important to determine whether the data points on phase B are greater than the greatest point achieved in phase A.

The baseline data will be examined to assess trends and whether a flat baseline exists. If a flat baseline exists, then 25D band will be used to determine if there is a significant change between phases. If there is a trend in baseline then the C & Z will be used to determine significance (more than eight observations and HR readings per phase).

A comparison between two slopes (Phase A acceleration line and phase B acceleration line) will be analyzed to determine if there are any significant changes in the acceleration line. A comparison of the two slopes, both visually and numerically, will indicate a clear difference with the phase B slope, which will demonstrate an accelerating trend, using an equal number of data points in both phases: Phase A and phase B will have at least 8 data points each. A significant improvement in the participant's scores from baseline to intervention phase can be confirmed by comparing trends using the C and Z statistics to

determine significant changes in variables e.g., measured stress levels and parent-child interactions, and the possible relationships that may exist as a result of the caregiver's participation in the program.

The data entry and the technology e.g., computers, Fitbit Charge, will be tested prior to the start of the program for reliability, accuracy and efficiency.

The COPM pre- and post-assessment data will be analyzed and compared with caregiver-identified goals to determine if the participants' (e.g., caregivers) needs were met and their new skills helped to work with identified challenges and created meaning as a result of their involvement in the program.

The PSI-SF pre and post assessment scores will be analyzed to determine whether any changes occurred in caregivers stress levels throughout the program.

Conclusion

This is a comprehensive and individualized evaluation plan that assesses a number of variables such as stress levels (both perceived and real-time measures with HR readings), parental competence (PSOC), and sensory sensitivities (SP), and the impact they have on participation and engagement in occupation (parenting and forming relationships), health and well-being. It will determine whether there are any existing relationships among the variables. If so, what mediating and moderating factors have the greatest impact on the behavioral changes. in families of children with ASD participating in and engaging in occupation (s) within a natural setting e.g., community at the WE C.A.R.E. 2 program. Through the use of accurate task analysis and the identification of barriers the trainers can modify and adapt the program to meet the needs of caregivers

and their children with ASD assist in maintaining routines and increasing participation. The utilization of interviews that are client-centered e.g., COPM and SP, as a form of assessment will assist the therapist in tailoring the program to the strengths and needs of the participants, in order to produce positive outcomes. The quantitative evaluation (e.g., HRV readings) will provide evidence that higher resting HRV is associated with flexible and adaptive top-down and bottom-up cognitive processing, which facilitates effective emotion regulation, in comparison to lower HRV and hyper-vigilant and maladaptive bottom-up and impaired top-down cognitive response to emotional stimuli. The various evaluations will assist in determining the different behavioral changes e.g., stress from maladaptive to adaptive negative and positive coping strategies among caregivers and their children. It will further examine whether a relationship exists between the different variables e.g., stress, self-efficacy and competence and its impact on the quality of parent-child interaction (e.g., amount of positive and reciprocal interaction) and parent-child relations. Occupational therapy (OT) is a science-driven profession and occupational therapists (OTs) have the knowledge and experience to evaluate the occupational needs of the clients (caregivers). OTs are trained to assess a client in order to identify those barriers that interfere with the clients' ability to engage in meaningful occupations while working closely with the client to set objectionable and attainable goals. These identified and set goals will motivate the client toward behavioral change by strengthening the therapist-client alliance throughout the evaluation process and will work toward the effectiveness of the intervention. Not only are these specific evaluations client-centered, the collection of data from the various

evaluations will provide more support on the efficacy of a yoga program with this population, using mixed methods (e.g., qualitative and quantitative data). The evidence provided from the pre-mid-post tests throughout this program will fill the gap for more evidence-based interventions (EBIs) in natural settings e.g., community that has a positive impact on community participation and integration for children with disabilities and their families. The assessment of parental stress will also help healthcare professionals to better adopt and adapt care that supports and strengthens the caregiver's ability to be an agent of change while promoting their health and wellbeing through a mindfulness program such as yoga.

CHAPTER FIVE – Funding Plan

Program Description

WE C.A.R.E. 2 is a theoretically grounded community-centered health promotion program that will provide more evidence to support the efficacy of a yoga intervention on managing stress of caregivers and their children with autism spectrum disorder (ASD) ages five to eight years of age. It is designed to provide an inclusive opportunity where caregivers and their children with ASD can be empowered with self-regulatory tools through the practice of coping strategies learned throughout the program, thus decreasing stress levels, gaining a sense of control, and feeling their sense of well-being and overall improvement in health and quality of life. Recent studies have found associations between higher parenting stress levels and psychological distress when raising children with ASD in comparison to rearing typically developing children (Weiss, et al., 2012). There is a need for more community-based interventions that focus on family-centered care for more positive outcomes (Kuhaneck, et al., 2015). An emerging field exists in teaching parents to implement strategies to increase their children's communicative and social development, which will fill the gap that exists in providing parent-to-parent and small group support, in order, to maintain and generalize learned skills (Patterson, Smith, & Miranda, 2012). The WE C.A.R.E. 2 community program will address the need for more effective interventions and resources for children with ASD and their families to address the core problems and a lack of professional support for parents within the community (Dunst et al., 2016) that improve resiliency (Pastor-Cerezuela, Gemma, Fernández-Andrés, 2016). This community intervention would provide the necessary

education and support to allow parents the opportunity to connect socially and emotionally with their child and the community (Hall et al., 2008). The importance of a well-designed intervention, using a step-by-step guide with specific breathing techniques and movements is a key factor in the carryover of skills (e.g., behavior, cognition, and self-regulation) among the adults (caregivers) and children in a yoga intervention (Radhakrishna et al., 2010; Rosenblatt & Gorantla, 2011). It will ensure the uniformity of the program and that all individuals involved in the program e.g., professionals and caregivers are familiarized, trained, and confident with the components of the program. This will support the increase in participation and interaction among participants to promote positive reciprocal interactions within a given activity (movement).

This nine-week parent-child yoga program aims to determine the efficacy of a community based occupational therapy intervention that decreases parental stress and strengthens caregiver resilience while raising their child. This evidenced-based intervention is centered around the well-being and quality of life of the family and is designed to meet the needs of the family in order to improve family function.

Context for Funding

The context for this program is to provide a more inclusive and cost-effective community program for families of children with ASD at a non-profit organization such as Cornell Cooperative Extension and Family Service League. Unfortunately, funding is limited in non-profit organizations and they depend on funding through donations and contributions from other non-profit organizations (e.g., Autism Speaks and affiliates) that supports the same businesses and families within the community.

Funding Plan Introduction

This program will be funded through one of the three universities that the author is affiliated with as an adjunct professor. The author is a mental health and pediatric occupational therapy fieldwork supervisor in non-traditional sites throughout Suffolk County, New York, who has gained mutual partnerships with local non-profit organizations. The equipment, office supplies, program assistants and facilitators will be built into the existing university budget and funded through tuition and fees. The space for the program will be provided, without a fee, at an existing facility that presently has programs for the targeted population, families of children with autism, and has been utilized as a fieldwork site for occupational therapy students. Other expenses such as wearable devices, a speaker to amplify music, and a music subscription may not be funded by the university and will be funded through a donation from the author and/or by other stakeholders such as Autism Speaks, other caregivers of children with autism, and other non-profit organizations e.g., Kids Run Long Island. Depending on the external resources the program can be adjusted from a simpler design to a more extensive research project to fit within the budget. Additional funds could enrich this program and support more intense studies that provide quantifiable data that measures up to the golden standard use of portable devices with a larger study group. The research can be continued with the next group of occupational therapy students that are fulfilling their fieldwork and capstone requirements. This will further support occupational therapy's role in implementing evidence-driven and community-based interventions and programs.

Needed Resources: Budget

Yoga is a feasible program that does not require much equipment to practice. The most expensive and most important purchase for the first year of this pilot program is the technology (five wearable devices) to assess the stress levels of caregivers. The importance of these devices is to record heart rate variability. The other expenses will include a portable speaker to amplify the music and create the mood and the props will aid in the modification and adaptation of the postures to optimize learning and performance for all learning abilities. Other resources that will be needed to create this safe and secure space for positive family outcomes will include props such as yoga, include mats and blocks, five medium-sized balls and yoga cue cards to provide a multisensory approach for learning. All these different forms of input will work to elicit the appropriate response and a sense of balance throughout the program and promote engagement and increased participation.

The focus for the second year of the program will be expanding on the number of participants from five to ten, depending on the outcome of the first year. If positive gains were noted as a result of the program, then the author would focus on the expansion of the program, so that more families (approximately 10) families depending on the funding and interest) could participate in the program. Ideally, the WE C.A.R.E. 2 Program would expand into a more intensive two-week summer program for a pediatric and mental health fieldwork within the next three years. Not only will this program expansion provide an inclusive opportunity for more families and their children with autism to learn, practice, and become part of their community, it will also benefit the

occupational therapy students, college, and the profession. This will educate the occupational therapy students on non-traditional fieldwork, community practice, and occupational therapy's role in health promotion. This program could be implemented into the 4-H summer camp at one of the non-profit organizations, where a mutual partnership has been established during fieldwork.

Table 5.1: Expenses for Pilot Program

Equipment/props	Description	Amount	Expense/ each	Total expense
Wearable device (Walmart)	Fitbit Charge HR Hear rate & Activity Fitness Monitor Wristband	5	\$64.99 + tax Free shipping	324.95 + 28.03 =\$352.98
Portable Bluetooth Speaker (Walmart)	UBL Harman Flip3	1	\$56.97 Free shipping	\$56.97
Yoga mats (roll) (YogaOutlet.com)	Everyday Mat Roll (105 foot) 5 mm	1	\$178.98	\$178.98
Blocks (YogaOutlet.com)	Everyday Yoga 3 inch Foam	20	\$6.98	\$139.60
Exercise Balls - Medium-sized (Amazon)	10 inch heavy duty small Pilates balls w/pump	2 sets of 3	\$15.98 + tax Free shipping	31.96
Yoga partner cards (kidsyogastories.com)	40 partner yoga pose cards	1	\$14.95+ tax+ shipping	\$14.95
Arts supplies for creative expression	\$100.00			\$100.00
Stipend to caregivers for participating	Gift card	5	\$30	\$150.00
Spotify subscription	Yoga /relaxing music	Per month	\$9.99	\$119.88
<u>Dissemination Plan expenses</u>				
NYSOTA Conference (members)	1 professor 3 students	4	\$350 - practitioner \$200 per student	\$ 950.00
Gas				50.00

Meals	4 people			200.00
Implementation Budget total				\$1,145.32
Dissemination budget total				\$1,200.00
Total				\$ 2,345.32

Program Implementation Costs

The implementation of this program will require more time than it will cost. Networking and presentations to educate the various organizations on the fieldwork and program objectives and benefits will be paid for by the university as part of fieldwork, along with the cost of labor, utilizing the occupational therapy students to assist in the implementation of the program. Materials such as the paper and printing costs required for the manual will be covered by the university and the fieldwork site. The implementation of the pilot program will be more cost effective, then the second year projection for the WE C.A.R.E. 2 program, due to the expansion of the program and opening the program to more participants (caregivers and children). This would require a meeting for a mutual agreement among stakeholders to expand the program to a more extensive program (Table 5.2). The expansion will involve a two-week inclusive program integrated into an already existing 4-H summer program. This will involve an increase in the number of participants with an increase in equipment and cost.

Potential Funding Sources

The main funding source for the manpower (students) and the author (facilitator) of this program will be the Division of Occupational Science and Occupational Therapy at the university and/or college affiliated with the fieldwork experience. The expenses

covered for fieldwork will include salary, manpower, handouts, manuals and support for the dissemination of the program e.g., conference expenses. Funding sources for the implementation of the program are described in Table 5.2.

Table 5.2: Expenses for the Expansion of the We C.A.R.E. 2 Program

Implementation				
Equipment/props	Description	Amount	Expense/ each	Total expense
Wearable device (Walmart)	Fitbit Charge HR Hear rate & Activity Fitness Monitor Wristband	5 additional	\$64.99 + tax free shipping	\$ 324.95 + 28.03 =\$352.98
Yoga mats (roll) (YogaOutlet.com)	Everyday Mat Roll (105 foot) 5 mm	3	\$178.98	\$ 536.94
Blocks (YogaOutlet.com)	Everyday Yoga 3 inch Foam	20	\$6.98	\$ 279.20
Exercise Balls - Medium-sized (Amazon)	10 inch heavy duty small Pilates balls w/pump	2 sets of 3	\$15.98 + tax Free shipping	\$ 95.88
Arts supplies for creative expression	\$100.00			\$300.00
Stipend to caregivers for participating	Gift card	10	\$30	300.00
Spotify subscription	Yoga /relaxing music	Per month	\$9.99	119.88
Dissemination				
NYSOTA Conference 2-day (member)	Author and 3 students	4	\$350.00/ Student-\$200	950.00
Meals (2 days)	Author and 3 students	4	\$100.00/person	400.00
Gas				50.00
AOTA Conference	Author and 3 students	4	\$ 451.00/full Student/full \$299.00	1,348.00 + 451.00 <u>1,799.00</u>
Transportation (AOTA conference)	Author and 3 students	4	\$700 Round trip	2,800.00
Meals (3 days)	Author and 3 students	4	\$150.00/per person	600.00
Implementation budget total				1,984.88

Dissemination budget total				6,599.00
Total				\$8,583.88

Table 5.3: Potential funding sources

<u>Fund Sources</u>	<u>Description</u>	<u>Areas for Funding</u>
Kids Run Long Island Non-profit 501(c) (3)	\$1,100 -1,300.00 annual award to a non-profit organization. A mission to inspire kids to be the best they can be through healthy living, fitness & mindfulness.	Implementation
Act Today national nonprofit 501(c)(3) organization	Awards grants of up to \$5,000 with priority given to families with household incomes less than \$100,000.	Implementation
Autism Speaks Bi-annual Norma and Malcolm Recreation Program	Summer Camp Programs – Day and overnight programs that provide a safe and nurturing environment where people with autism can enjoy a variety of therapeutic activities and sports, and arts programs. A source of needed respite for families and caregivers. Physical Fitness and Sports Programs – including a wide range of athletic activities and team sports, as well as health and wellness program	Implementation
University/College of Occupational Science and Occupational Therapy	AOTA & NYSOTA conferences	Dissemination

Conclusion

The WE C.A.R.E. 2 intervention will be an inclusive parent-child yoga program that will work to improve the QoL among families of children with ASD within the community. It will provide an opportunity for caregivers and their children to participate

in a health promotion program that will address the stress experienced when raising a child with ASD by providing education, support, and self-regulation techniques and strategies for the management of behaviors and stress. The funds will support, not only the families of children with ASD, but enhance learning for occupational therapy students and programs as well as for non-profit organizations looking to expand on their existing programs by providing more inclusive opportunities within their community for all learners and abilities. The cost of the pilot program (\$2,345.32) is feasible and includes both implementation and dissemination of the program. The results from the pilot program will further determine the need for the extension of the program or determine whether changes need to be made to the existing program to justify the increase in the cost from \$2,345.32 to \$8,583.88 for the extension of the program. A meeting with the major stakeholders e.g., universities, non-profit organizations, caregivers, will be planned to address the two-year plan, the outcome from the pilot program, the costs involved and any changes that may be necessary to defray costs during the implementation of dissemination process. This chapter has identified those major stakeholders responsible for supporting this two-year program for the above purposes. The WE C.A.R.E. 2 Program can be enhanced depending on the outcome and the benefit of the program to the stakeholders and the funds garnered for learning experiences for all those involved in the outcome and for the occupational profession as a whole.

CHAPTER SIX – Dissemination Plan

Program Description

WE C.A.R.E. 2 is a nine-week, parent-child yoga health promotion program, centered on the empowerment and wellbeing of the family by decreasing stress levels of the caregivers and their children with autism spectrum disorder (ASD). This will provide an inclusive opportunity that educates, supports, and provides practice of strategies and tools for the self-management and regulation of emotions to improve the health and quality of life, thus improving family function. Through the knowledge and practice of various breathing techniques and movement experiences each caregiver will gain a greater awareness and understanding of his/her physiological responses and how to adjust their behavior to adapt to changes and/or stressful situations in a more proactive manner that creates a positive change in their child. This will address the core problems e.g., stress, lack of control, maladaptive behaviors and lack of positive and reciprocal interactions that caregivers are experiencing while raising their children with autism spectrum disorder (ASD).

Dissemination Goals

The WE C.A.R.E. 2 program will be able to provide more inclusive opportunities in the community by gaining the support from the community to sustain the program. Community involves mutual partnerships such as caregivers of children with disabilities, autism spectrum disorder, organizations with the same mission e.g., universities, American Occupational Therapy Association (AOTA), New York Occupational Therapy Association (NYSOTA), Autism Speaks and these gained partnerships will assist in

accomplishing the long- and short-term goals over the next two years. The following are those long- and short-term goals:

Long-term goal. The program results, the quantitative and qualitative evidence, will be shared with “big data “e.g., Healthy People 2020 (Fertman & Allensworth, 2017) to stakeholders which will strengthen the support for the expansion of the WE C.A.R.E. 2 program. The expansion will allow for more families to benefit from the WE C.A.R.E. 2 Program (10 to 20 participants). The data from the pilot program will add to the existing evidence on the effectiveness of a yoga program on decreasing the stress levels of caregivers and improving the wellbeing and quality of life for families of children with ASD. This will work to adjust to any changes without losing the functional components of the program such as participants, stakeholder support, and funding (Fertman & Allensworth, 2017). This will be accomplished in the specific areas:

Short-term goal. Program results will be organized, collected, and recorded in charts and placed on a slideshow for a one-hour presentation to stakeholders, including families of children with ASD, occupational therapy programs, and non-profit organizations. This meeting can be extended to other potential stakeholders (e.g., out-of-state universities with occupational therapy programs and other non-profit organizations who provide programs for children with disabilities), while remaining professional and rooted in OT values e.g., respectful, ethical).

Short-term goal. Collaborate with occupational therapy students at a local university to prepare a poster for New York State Occupational Therapy Association (NYSOTA) conference to share the intervention with other professionals.

Short-term goal. Presentation (90-minutes) at NYSOTA to share the details of the effectiveness of the program and the outcomes measures, which will include parental stress and quality of life for caregivers and their children with (ASD).

Short-term goal. Be a guest speaker at the different occupational therapy programs to share with students and educators on emerging practices and contemporary practices. This will sustain the program by gaining a rapport with different stakeholders (educators and students), sharing knowledge about the program, and increasing the interest in the fieldwork, which will increase staffing and facilitators for the program.

Short-term goal. A second presentation (90- minutes) at the International Yoga Therapy Association (IYTA) to share the details on the effectiveness of a yoga program on parental health and quality of life. This will provide more evidence for complementary and alternative therapies with this population. This will improve the interprofessional collaboration with research and interventions.

Short-term goal: Monitor the responses from the public and publish information in an article, newsletter, and podcast with other professionals and associations e.g., physical therapists, yoga therapists, and organizations with target population. This will help gain media support to sustain the program.

Long-term goal: Provide more non-traditional level I & II fieldwork opportunities for occupational therapy and occupational therapy assistant students in Long Island occupational therapy programs. This will recruit more staff (students) to replace the last group of trained staff to ensure the sustainability of the program.

Short-term goal: Present a poster at American Occupational Therapy Association (AOTA) on the WE C.A.R.E. 2 program and network with other professionals and potential stakeholders to support the expansion of the program.

Short-term goal: Present a session or workshop at American Occupational Therapy Association (AOTA) on the WE C.A.R.E. 2 program and network with other professionals and potential stakeholders to support the expansion of the program.

Short-term goal: Advocacy for the profession and the program. Interview for W.E.L.L. Matters podcast and/or radio station on outcomes of WE C.A.R.E. 2 program. This will increase awareness for this health promotion program and gain more partnerships through these different mediums.

Short-term goal: Provide at least one non-traditional fieldwork experience semester at an existing organization in the community each year.

Short-term goal: Increase the number of students with a non-traditional fieldwork experiences each semester over the next two years. The students will gain an understanding for occupational therapy's role in health promotion.

Short-term goal: Increase the number of students from eight to sixteen with a non-traditional fieldwork experience each semester over the next two years. The students will gain an understanding for occupational therapy's role in health promotion and emerging practices.

Target Audiences

Primary audience: The primary audience for the dissemination of the WE C.A.R.E. 2 health promotion program will be the participants (caregivers and their children with ASD). This program will teach emerging strategies for self-management of stress and improve resiliency when raising their child with ASD. This program is an inclusive opportunity that empowers caregivers and their children with ASD with education on their child's diagnosis and symptomology, support from staff and other caregivers, and provide tools to help them manage their stress and their child's behaviors. This will work toward more engagement and connection with their child and the community.

Secondary audience: The secondary audience for dissemination of the WE C.A.R.E. 2 health promotion program will be the mutual partnerships gained with occupational therapy universities/administrators, who have a similar mission as the WE C.A.R.E. 2 program. The gained partnerships will support the sustainability of the program by providing the site (facility), administrators and fieldwork coordinators of occupational therapy programs, and funding for the materials/equipment for the community yoga program.

Although the students play a significant role in the efficacy of the program, the

University administrators and fieldwork coordinators will be the decision makers in the placement for non-traditional fieldwork, community learning experiences, and provide an opportunity for emerging practices. The students will be the mechanism through which the dissemination of a community-based program will be carried out during the educational and fieldwork experience. Throughout the learning process, the students will gain a greater understanding of the role of occupational therapy in health promotion, the importance of advocacy, the benefits of a community practice, and the importance of a therapeutic relationship with a client-centered approach.

The main goal is to align with AOTA's Vision 2025, which states "*As an inclusive profession, occupational therapy maximizes health, well-being, and quality of life for all people, populations, and communities through effective solutions that facilitate participation in everyday living.*" (American Occupational Therapy Association, 2017). This will be accomplished when building a community practice and collaborating with universities and organizations (e.g., private and public) to help educate the occupational therapy students, clients, and the community (organizations and agencies) on occupational therapy's role in health promotion. This will be achieved when presenting the program(s) at NYSOTA and AOTA conferences and stakeholder meetings. University educators, including fieldwork coordinators and occupational therapy students will be invited to present the outcomes with the author.

Key Messages for Primary Stakeholder

The program's mission is to provide an inclusive opportunity in the community where caregivers and their children with ASD can address their emotional and physical

needs while engaging in a community program, WE C.A.R.E. 2. The aim of this health promotion program, WE C.A.R.E. 2, is to provide an opportunity to engage and have fun with your child and other families, with similar challenges, while learning different coping strategies e.g., breathing, yoga postures, and meditation.

This evidenced-based parent-child yoga program will provide an opportunity for caregivers to support and interact with one another in a safe, comfortable, and supportive environment within the community. Through C.A.R.E. (Compassion, Awareness, Respect, and Engagement), the WE C.A.R.E. 2 program will give the caregiver the confidence and practice in utilizing strategies and techniques to manage your stress levels and your child's behavior and stress to manage everyday challenges and transitions with confidence. This program will be offering the following:

- A cost-effective health promotion program that provides the “just right” challenge approach through individualized guidance and support by a trained professional (an occupational therapist) and occupational therapy student for each parent-child group.
- Encouragement and opportunity to caregivers and their children to participate in a community activity that is supportive and considers the needs of each individual.
- An opportunity to learn stress management techniques and self-regulatory skills that you can use to deal with stressful situations and cope with everyday challenges in a simple and effective manner. Once learned, these techniques can be reinforced with your child to assist them in self-regulating.

A caregiver will be invited to share their experience and the gains made by participating in the program. This will provide testimony at the meeting with other stakeholders when looking to support the expansion of the program. This testimonial will be in the handouts presented in the meetings, presentations, and poster boards for conferences. The testimony could be placed in the emails sent to other caregivers to gain an interest in the program and increase the number of participants.

Secondary Stakeholders

Secondary stakeholders include occupational therapy administrators/fieldwork coordinators. I will be choosing one of three fieldwork coordinators from an occupational therapy program as a key spokesperson to educate the administrators and faculty on the aim of the program, the benefits to the occupational therapy students the community, and the occupational therapy profession and institution. I have gained a strong alliance with all three coordinators/educators and I have had the pleasure and opportunity to collaborate with all of them. Our goal has been to align with the ACOTE standards in providing more non-traditional fieldwork experiences for the students. I will continue to collaborate with these professionals when presenting at NYSOTA and AOTA conferences on this topic (e.g., posters, workshops) and share the data and outcomes from the programs and presentations with other professionals and non-profit organizations for the sustainability of the program and to educate and advocate for the occupational therapy. This program will be offering the following:

- A cost-effective and evidenced-based health promotion program that provides the community with trained professionals (an occupational therapist) and

occupational therapy students.

- Educate occupational therapy students on

Dissemination Activities

First Year Dissemination Plan

- **Written materials:** The data from the pilot program will be organized, formulated, and recorded to support the mission of WE C.A.R.E. 2 as well as the mission of the non-profit organization. This will provide greater support for the expansion of the program during presentations and meetings. Handouts, e.g., outline and fact sheet, will be prepared for meetings and presentations to Universities, caregivers, and other stakeholders. Conference participants at NYSOTA will be asked to fill out survey for gained awareness of program and determine the level of interest as a collaborative partner.
- **Communication:** First, would be to have a meeting with the facilitators of the program to discuss the effectiveness of the program. Second, follow up with parents three months after program. Third, the author will make phone calls and send emails to set dates for meetings/presentations (e.g., posters, workshops) to other existing and potential stakeholders. Follow up via email and/or phone with interested professionals from conference and meetings from a contacts list.
- **Presentation (s):** The presentation(s) may require more funding, depending on the audience, so increased support through networking, interviewing potential stakeholders (e.g., podcasts), and presentations at various events such as luncheons with various organizations (e.g., Autism Speaks) and NYSOTA

conference.

Second Year Dissemination Plan

- **Written materials:** The data from the pilot program will be organized, formulated, and recorded to support the mission of WE C.A.R.E. 2 as well as the mission of the non-profit organization. This will provide greater support for the expansion of the program during presentations and meetings. Handouts, e.g., outline and fact sheet, will be prepared for meetings and presentations to stakeholders. Publish article in American Journal of Occupational Therapy. Conference participants at NYSOTA will be asked to fill out survey for gained awareness of program and determine the level of interest as a collaborative partner.
- **Communication:** First, would be to have a meeting with the facilitators of the program to discuss the effectiveness of the program. Second, follow up with parents 3 months after program. Third, the author will make phone calls and send emails to set dates for meetings/presentations (e.g., posters, workshops) to other existing and potential stakeholders. Follow-up via email or phone with interested professionals contact list collected at conferences and meetings.
- **Presentation (s):** The presentation will be tailored to the audience, depending on the type and amount of support needed e.g., networking, interviewing potential stakeholders (e.g., podcasts), and presentations at various events such as luncheons with various organizations (e.g., National Autism Association) and American Occupational Therapy Association (AOTA) conference.

Table 6.1: Dissemination Goals

First year	Purpose
Organize, formulate, and record data from pilot program and on a spreadsheet with charts	<ul style="list-style-type: none"> • Share effectiveness of the program • Discuss quantitative data from wearable devices, percentages from checklist, and Sensory Profile. • Discuss qualitative data from questionnaires, COPM, and Stress Scale • Determine and share outcomes among caregivers and children with ASD.
Prepare a poster board and a proposal for NYSOTA conference	<ul style="list-style-type: none"> • This will assist other practitioners in adopting the program in various settings. • Translate research into practice by attending to the “core elements” that led to the effectiveness of the program e.g., occupational therapy students as staff and yoga as a flexible and feasible program requiring very little resources to implement.
Prepare for presentation to stakeholders, including caregivers and other parents of children with ASD, non-profit organizations (e.g., site of program and funding agencies), university administrators/educators, occupational therapy students, and fieldwork coordinators	<ul style="list-style-type: none"> • State goals, results, and outcomes. Add quotes from participants (e.g., parents, children) or have one of the caregivers speak about their experience. • Translate research into practice by attending to the “core elements” that led to the positive outcomes • Feasibility to carry out program such as trained staff & fieldwork experience • Conference survey • Follow up with contacts from survey for potential stakeholders
Second Year Dissemination Goals	Purpose
Organize, formulate, and record data from expansion of program and on a spreadsheet with charts	<ul style="list-style-type: none"> • Share effectiveness of the program • Discuss quantitative data from wearable devices, percentages from checklist, and Sensory Profile. • Discuss qualitative data from questionnaires, COPM, and Stress Scale • Determine and share correlations related to quality of life and health among caregivers and children with ASD.
Prepare a poster board and a proposal for AOTA conference	<ul style="list-style-type: none"> • This will expand the program to a wider audience, including other practitioners in adopting yoga as an intervention in various settings. • Translate research into practice by attending to the “core elements” that led to the effectiveness of

	<p>the program e.g., occupational therapy students as staff and yoga as a flexible and feasible program requiring very little resources to implement.</p> <ul style="list-style-type: none"> • Conference survey • Follow up with contacts from survey for potential stakeholders
<p>Prepare for presentation to stakeholders, including caregivers and other parents of children with ASD, non-profit organizations (e.g., site of program and funding agencies), university administrators/educators, occupational therapy students, and fieldwork coordinators</p>	<ul style="list-style-type: none"> • State goals, results, and outcomes. • Add quotes from participants (e.g., parents, children) testimonials or have one of the caregivers speak about their personal experience with the program. • Translate research into practice by attending to the “core elements” that led to the success of the program • Feasibility to carry out program such as trained staff & fieldwork experience
<p>Gain more sustainable partnerships for future collaborations</p>	<ul style="list-style-type: none"> • Creative networking meetings/events, such as luncheons and breakfasts to gain more partnerships to sustain program. Interviewing other organizations and CEO’s of businesses/organizations (non-profit and for profit) with a similar mission/goal
<p>Publish article (anticipated)</p>	<ul style="list-style-type: none"> • American Journal of Occupational Therapy (AJOT)

Budget

The first year of the dissemination plan will require more time than funding. The majority of time will be invested in networking, organizing and gathering information from the program, preparing for the presentations and meetings i.e., phones, emails, and traveling to organizations, sites, and conferences. Materials and printing for the presentations will be covered by the universities and colleges, where I am employed as a fieldwork educator. Financial expenses for travel to present posters, sessions, and/or workshops at the different conferences are listed in Table 6.2. Budget expenses include registration fees, travel, lodging, and meals. The first-year dissemination budget is \$

1,400.00. The dissemination budget for the second year would be \$5,023.00. The total cost for the two-year dissemination would be \$ 6,423.00.00. The total dissemination cost could be reduced to \$5,774.00, if the number of occupational therapy students attending the AOTA conference goes down to two.

Table 6.2: Dissemination Plan Expenses

Dissemination Expenses		# of people	Cost per person	
First Year				
NYSOTA Conference 2-day (member)	Author and 3 students	4	\$350.00/ Student-\$200	950.00
Meals (2 days)	Author and 3 students	4	\$100.00/person	400.00
Gasoline				50.00
Subtotal				\$ 1,400.00
Second Year				
Publication Fee				275.00
AOTA Conference (full registration)	Author and 3 students	4	\$ 451.00 \$ 299.00	451.00 897.00
Transportation (AOTA conference)	Author and 3 students	4	\$700 Round trip	2,800.00
Meals (3 days)	Author and 3 students	4	\$150.00	600.00
First Year subtotal				1,400.00
Second Year subtotal				5,023.00
Total Dissemination				\$6,423.00

Conclusion

The dissemination plan will target caregivers of children with ASD and occupational therapy administrators and fieldwork coordinators. The main focus for this dissemination plan will be occupational therapy conferences in the United States, where poster boards and presentations will educate other occupational therapy educators, practitioners, and professionals on how a health promotion program such as parent-child yoga can improve health and facilitate health behavior change. In addition to conferences, dissemination will be directed at journals and gaining the attention of occupational therapy educators and administrators. Initially, the manuscripts will be submitted to AJOT and then other professionals will be targeted e.g., yoga therapists and psychologists, following the completion of the extended program. This dissemination plan will target local audiences and then extend into more national and international audiences each consecutive year, if agreed upon by the major stakeholders and funds are available to carry out the plan as intended.

CHAPTER SEVEN - Conclusion

The level of stress experienced by caregivers and families with autism spectrum disorder (ASD) is impacting their physical and mental health as well as social functioning (Vasilopoulou & Nisbet, 2016). Recent studies have found associations between higher parenting stress levels and psychological distress when raising children with ASD in comparison to rearing typically developing children (Weiss et al., 2012; Weiss, et al., 2014). There is increasing support for interventions that focus on adaptive skills and symptom reduction, parent- mediation, and parent training (Vasilopoulou & Nisbet, 2016). The three major stressors that have an impact on the parent's ability to cope with their child are the severity of the child's disability, child's caretaking demands, and maladaptive behaviors of their child (Pastor-Cerezuela et al., 2016).

The WE C.A.R.E. 2 yoga program will address the cognitive and physiological responses of the caregiver by changing the way the caregiver thinks and responds to the maladaptive behaviors of their child and the way they will deal with stressful situations themselves. Through the knowledge and practice of various breathing techniques and movement experiences, each caregiver will gain a greater awareness and understanding of his/her physiological responses and how to adjust their behavior to adapt to changes and/or stressful situations in a more proactive manner that creates a positive change within themselves and in their child. This will address the core problems e.g., anxiety, maladaptive behaviors such as yelling, hitting, and lack of positive and reciprocal interactions that caregivers are experiencing while raising their children with ASD. The strategies learned during the WE C.A.R.E. 2 program will afford the opportunity to

develop a more individualized intervention plan, where the caregivers set goals and objectives, to meet their needs. This family-centered intervention within the community will provide individualized parental support with trained facilitators as an effective way to manage behaviors, in addition to receiving education about challenging behaviors. A manualized program that will be given to the facilitators and caregivers in program will provide strategies to optimize performance and reduce both challenging behaviors and parenting stress. Direct observations of challenging behaviors and biological markers of stress, using a Fitbit watch, will be an appropriate alternative to measuring stress levels of caregivers, along with self-assessments e.g., Parental Stress Index (PSI-SF). Problem solving strategies (top-down processing), instead of emotion-based reactions (bottom up processing), will be implemented into the sessions for the caregivers to use as a coping strategy with each moment- to -moment experience. This will help to produce more adaptive and healthier behavior choices in various contexts such as the community and the home.

This health promotion program will align with two global organizations, World Health Organization (WHO) and the National Institute of Health and Care Excellence (NICE). WHO describes different ways to create healthy environments or opportunities to promote health using a prevention strategy that enables people to have increased knowledge and control over their health, requiring an alliance from different agencies e.g., governmental, non-governmental organizations (NGO's). This will create healthy environments or opportunities (World Health Organization, 2009). NICE has two principles that will help to enable individuals and communities toward behavior change.

The first one is to assist families in gaining a sense of more control over situations by providing a number of cognitive, social and environmental resources to encourage the resilience of people living in difficult circumstances (NICE, 2007). NICE also recognizes the important role that behavior plays in people's health. The WE C.A.R.E. 2 program can address all these areas with the strategies and tools provided to the caregivers and their children that strengthen their resiliency and empower them to be satisfied in their occupation as a parent. The WE C.A.R.E. 2 is an evidenced-based community program that will provide the support, education, and resources needed with a group of five caregivers who have a shared interest, and their children with ASD. This flexible opportunity will afford the participants to self-reflect and practice self-regulation techniques such as breathing, yoga postures, and meditation in a supportive, non-judgmental, and adaptable environment. Yoga can potentially improve attention and bring about change by creating a sense of balance (e.g., emotional and physical) during the fight or flight response to reduce the physiological responses while stressed or in crisis (parasympathetic system more dominant and stabilizing the autonomic nervous system) (Sotoodeh et al., 2017; Sullivan et al., 2018; Bögels, & Restifo, 2014). This allows the caregiver to be more reflective, reduce stress, reduce parental preoccupation due parental and/or child mental health issues. Through this program, we aim to improve the quality of life for caregivers and children with ASD.

APPENDIX A: Executive Summary

Introduction

The Center for Disease Control and Prevention (CDC) considers Autism Spectrum Disorder (ASD) an important public health concern and claims to be committed to providing important data on ASD and assist in early detection through the development of resources, along with the search for risk factors and causes. In recent years, the overall prevalence of ASD has significantly increased from 14.8% in 2012 to 16.8% in 2014 per 1,000 children (sample of 8-year-olds). The CDC estimates that 1 in 59 children (sample of 8-year-old children from 11 US communities) are affected by ASD (Centers for Disease Control and Prevention, 2018) and considers this to be a lifelong developmental disability that affects a person's communication, social skills, and behavior. The complexity and uniqueness of symptoms (e.g., imitation, shared attention, difficulty relating to people, things and events, social interaction and communication problems, and hyper- or hyperactivity to sensory experiences and restricted and repetitive patterns of behaviors) among children with ASD has extended onto their families (American Psychiatric Association (APA)). As a result of the high prevalence of ASD, there are impaired social interactions and family and community relations, which are creating high stress levels for families (Kuhaneck, Madonna, Novak & Pearson, 2015; Lindo, Klienmann, Combies & Frank, 2016). The quality of the family's functioning has a significant impact on the child's cognitive and social functioning, along with the negative effects on the physical and emotional health of families (Kuhaneck et al., 2015). The communication and social impairments can lead to isolation and can heighten co-

morbid conditions such as depression and anxiety in children with ASD and their caregivers (Blainey, 2017; Schiltz, 2018). This added stress can lead to distress and can have an impact on the caregiver's and their family's health and well-being.

A health promotion program such as WE C.A.R.E. 2 that incorporates this approach can have the potential to enhance the quality of life for caregivers and their children by changing the way the issues are addressed and managed using a more proactive and problem-solving approach. This can create more meaningful and productive tangible solutions to the increasing and complex problems related to raising a child with ASD.

WE C.A.R.E. 2 Program

The WE C.A.R.E. 2 program is a nine-week evidenced-based community pilot program incorporates yoga and mindfulness to five dyads consisting of caregivers and their children (ages five to eight years) with high functioning autism (IQ > 85). This health promotion program will provide support, resources, and tools that aim to facilitate and guide the caregiver and their child toward healthy behavior changes such as decreasing stress/anxiety and promoting positive social engagement and family relations through the use of stress management techniques (e.g., breathing, yoga postures).

According to the National Institute of Health and Care Excellence (NICE), two principles that will enable individuals and communities toward behavior change are to develop more control (or enhancing their perception of control) over situations and providing a variety of cognitive, social and environmental resources to boost the

resilience of people living in difficult circumstances (NICE, 2007). NICE recognizes the important role that behavior plays in people's health.

WE C.A.R.E. 2 is an evidenced-based parent-child yoga program that will provide an opportunity for caregivers to support and interact with one another in a safe, comfortable, and supportive environment within the community. Through C.A.R.E. (Compassion, Awareness, **R**espect, and **E**ngagement), the WE C.A.R.E. 2 program will give the caregiver the confidence and practice in utilizing strategies and techniques to manage their stress levels and their child's behavior and stress, in order, to manage everyday challenges and transitions with confidence and consistency. Both the cognitive and physiological responses of the caregiver will be addressed by focusing on the way caregivers think and respond to maladaptive and challenging behaviors of their child. The opportunities provided throughout the program will allow the caregivers with opportunities to self-reflect and adapt or adjust to situations using more proactive behaviors and top down processing (problem-solving). The program's mission is to provide an inclusive opportunity in the community where caregivers and their children with ASD can address their emotional and physical needs while engaging in a community program. As a health promotion program, WE C.A.R.E. 2, is to provide an opportunity to engage and learn different coping strategies e.g., breathing, yoga postures, and meditation within their community while experiencing fun with their child and other families in a supportive environment. A mindful parenting approach is another way to address high parental stress that may have been brought on by the demand(s) exceeding the resources available to the caregiver, and for parents with mental health concerns when

dealing with the challenges of raising their child with ASD (Bögels & Restifo, 2014). Stressors associated with raising a child with ASD include the need to have rigid or structured routines, which can restrict the family's lifestyle and create social isolation (Bishop, Richler; Davis & Carter, 2008; DeGrace, 2004). This may hinder the development of typical family routines. The lack of social support has been identified as a moderator of negative outcomes for parents of children with autism (Dunn et al., 2001).

A group-based intervention such as parent training programs that incorporates mind-body practices can provide parents the opportunity to develop relaxation and coping strategies with a network of social support to promote healthy behaviors and healthy development for the child and caregiver.

Objective or solution to problem

Healthy People 2020 emphasizes the importance of health-related quality of life (HRQOL) and well-being and has established goals that promote quality of life, healthy development, and health behaviors across all life stages (Office of Disease Prevention and Health Promotion, 2016). Healthy People 2020 relates well-being as part of HRQOL and assesses the positive aspects of an individual's (i.e., caregiver) life, such as positive emotions and life satisfaction, in order to maximize his or her physical, mental, and social functioning in the context of supportive environments (Office of Disease Control and Prevention and Health Promotion, 2016). Mind-body therapies are feasible and tangible with a variety of populations, including children and adults with ASD (Hourston & Atchley, 2017) that would help caregivers manage their behaviors

through stress management techniques such as breathing and mindfulness. According to the National Center for Complementary and Integrative Health (NCCIH), Sept. 2017, yoga is one of the top ten complementary health approaches used by more than 13 million adults in the U.S. (NCCIH, 2017).

The incorporation of a mindfulness practice such as yoga will allow the caregiver and the child the time to perceive each situation with greater flexibility, accuracy, and awareness. This provides an individual (e.g., caregiver, child) with opportunities in a less reactive and non-judgmental manner with greater acceptance and awareness of whatever is taking place on a somatic, cognitive, affective, or behavioral level (and therefore no longer avoidant or reactive) to re-evaluate or reframe the perceived situation.

The lack of awareness, lack of training, lack of funding, and lack of support are the major areas of concern and have had a significant impact on the development of programs, which, in turn, has had an adverse effect on the health and well-being of families. Occupational therapists can help fill this gap in the community by assessing the needs of children with autism and their families by providing programs such as WE C.A.R.E. 2 that enable families to participate in everyday activities with movement and breathing techniques that assist each individual with self-regulatory techniques.

Evaluation

The WE C.A.R.E. 2 program will improve the QoL for families of children with ASD through the use of evidence-based interventions that assess the needs of the families and the effectiveness of the program. The various evaluations will help to sustain the program for another year, in order, to extend the program and service more families (five

to ten). There will be a total of five assessments with qualitative and quantitative data to determine the effectiveness of the program. Among those Pre- post tests administered will involve scales, (e.g., perceived stress scale- short form (PSI-SF), Brief Cope), a questionnaire (e.g., Parenting Sense of Competence (PSOC) an interview with the caregiver (e.g., Canadian Occupational Performance Measure (COPM), and a Sensory Profile (SP) to focus on the needs of the participants (child in the program). All these assessments will determine the behavior changes e.g., physiological and cognitive has occurred as a result of the components in the program. Wearable technology e.g., Fitbit Charge 3 will detect physiological biomarkers (heart rate-HR) and heart rate variability (HRV) will be calculated to determine the physiological changes that have occurred as a result of the coping strategies learned in the program. The collection of data will record the behavioral and physiological changes and determine the effectiveness of the program and sustain the program for a more intense and lengthier program that services more families. A six month follow up assessment via phone will be utilized to determine the longevity of coping strategies when dealing with stressful situations in their natural environment e.g., home, community.

Conclusion

The WE C.A.R.E. 2 is a community-based parent-child yoga program that will address the occupation-based needs (e.g., social interactions, parenting skills) by providing access to the support, resources, and tools that are so desperately needed in the community. WE C.A.R.E. 2, incorporates compassion, awareness, respect, and engagement (C.A.R.E.) during movement and social groups to address the

socioemotional and physical needs of caregivers and their children with ASD. The mission statement of WE C.A.R.E. 2 is to promote social justice, inclusion, and participation of families of children with ASD by offering support, resources, and programs within the community that are evidence-based and work to improve the QoL for children with autism and their families.

The WE C.A.R.E. 2 nine-week yoga program will promote the health and wellbeing of caregivers and their children with ASD by providing education, support, and tools that will create a change in the cognitive and physiological responses of the caregivers and their children to manage challenging behaviors. The increase in support through the promotion of a community program and funding will help to sustain the program and improve the quality of life for people with ASD and their families. Through a supportive and caring environment, caregivers and their children will gain positive outcomes from more programs that will allow them to develop positive relationships within their community.

Appendix B: Fidelity Checklist

FIDELITY CHECKLIST

Date of Entry: _____ ID#: _____ Session#: _____ Caregiver: _____ Facilitator: _____ Child: _____

Modified Fidelity Checklist adapted from Kaur, M., Bhat, A., Getchell, N., Lobo, M., & Pescatello, L. (2016). *Creative Yoga Intervention for Children with Autism Spectrum Disorder*, ProQuest Dissertations and Theses.

	Training Components	Max points (32)	Score	Feedback for Facilitator
Introduction – 9 points				
Introduces & shows pictures of activities & postures to the child.	Each trainer shows all the activities for the session and points to cue cards with activities	1 point	-	-
Ready position & Ready response	Ready position is modeled by trainer/facilitator. Trainer makes sure that the child is ready to start session e.g., sitting on mat with back touching caregiver and hands by their side. - Trainer asks the child, “Are you ready” or “Let’s get ready”? Child scores a point if child is already in correct position and attentive.	1 point		
Trials	1. Trainer sings “Hello” song and introduces themselves (Child is attentive e.g., remains seated and doesn’t exhibit excess movement 2. Trainer sings “Hello” song and introduces themselves and leaves time and invites the child to say his/her name	2 point (1 point per trial)	-	-
Session theme (asked during second trial of poses)	Trainer asks the child, “So what are we going to do next? Can you point to the picture card? Each child will get a chance to pick a pose to begin the theme. This will be chosen before the start of the session. Name and picture will be on the wall.	1 point		
Trials	1 st trial – facilitator models posture and practices with caregiver. 2 sitting, 2 lying, & 2 standing poses with the child. Score points if child attempts the poses. 2 nd trial – Trainer repeats all the poses	6 points (1 point per pose)		

	again with the child on a session theme. Score points if child attempts the poses.			
Partner poses	Parent/child practice 2 poses together with the child.	2 points		
Social praise – Gestural & Verbal	Gestural: Model provides Hi-fives, low-fives, fist bumps and waits for response (at least 1). Verbal : Facilitator provides verbal reinforcement (at least 1 prompt).	2 points (1 point for each prompt) 1 point		

	Training Components	Max points (32)	Score	Feedback for Facilitator
Guided Imagery (meditation)	Everyone relaxes while listening to guided meditation.	1 point		
Farewell – 7 points				
Introduce game, using Pictures	Trainer asks the child, “So what are we going to do last? Can you point to it?”	1 point		
Ready position	Trainer makes sure everyone is ready and in position e.g., seated on mat. Child may need to be guided back to appropriate place by asking, “Are you ready to say goodbye?”	1 point		
Trials	- Bye to the child – Trainer sings the whole song and says bye to the child. - Bye to trainers/facilitators – Trainer waits for child to sing and prompts the child to say “good bye”.	2 points (1 point per trial)		
Help for clean up	Trainer asks the child to roll the mat and help in clean up.	1 point		
Overall Session Characteristics – 11 points				
Session	<ul style="list-style-type: none"> • <input type="checkbox"/> Introduction • <input type="checkbox"/> Breathing game • <input type="checkbox"/> Partner game • <input type="checkbox"/> Relaxation/meditation • <input type="checkbox"/> Social Game • <input type="checkbox"/> Goodbye song 	8 points (1 point per activity)		

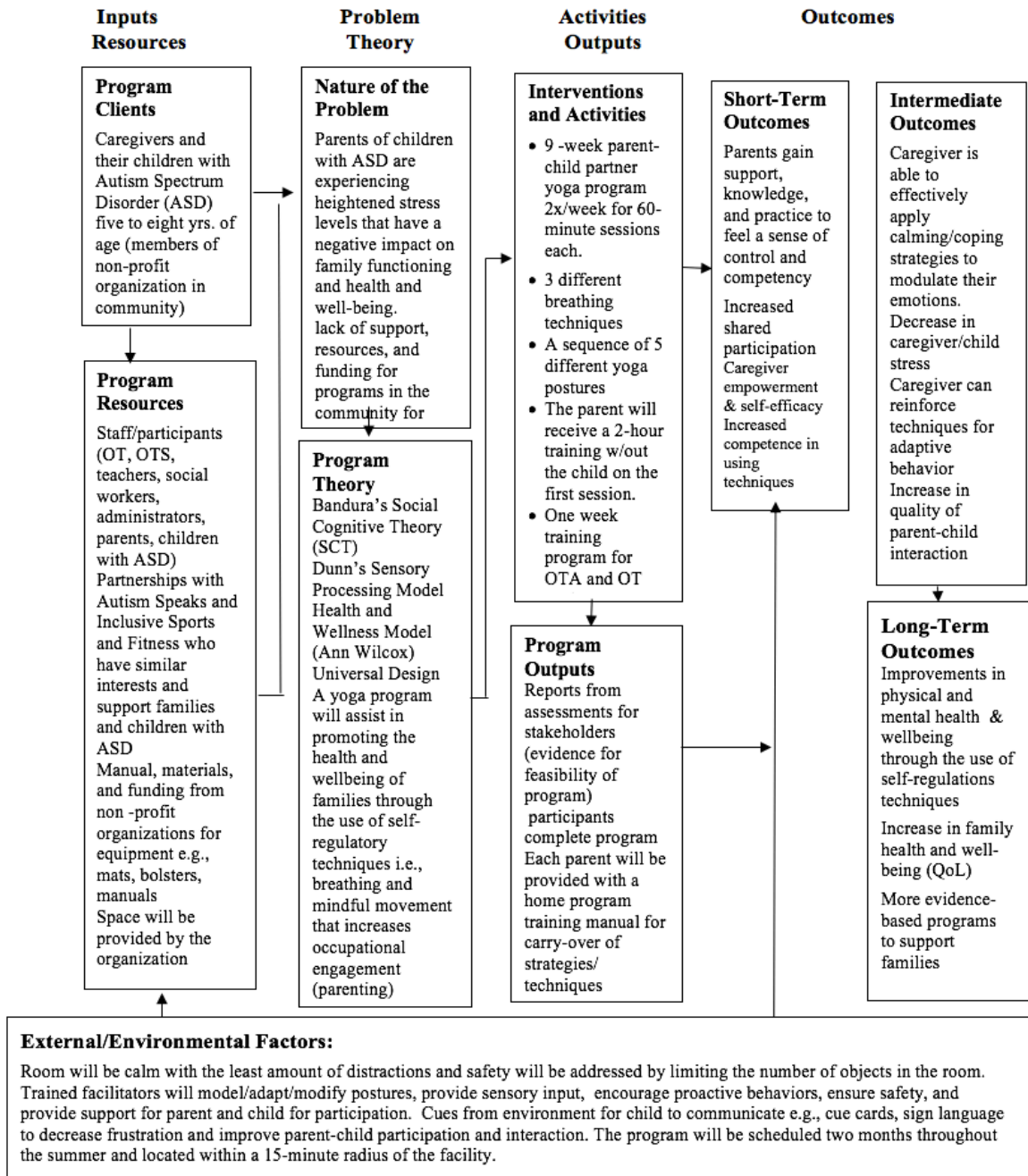
Eye contact	Trainer makes sure to obtain eye contact with the child while asking any question or while providing any commands. If the child does not provide eye contact, the trainer prompts by saying, “Can you look at me _____ ?	1 point		
Incremental prompts	<p>Within each condition, the trainer provides incremental prompts as necessary to get the child to copy him/her.</p> <ul style="list-style-type: none"> • <input type="checkbox"/> Visual model • <input type="checkbox"/> Verbal prompts • <input type="checkbox"/> Hand on hand assistance 	1 point		

Appendix C: Program Design



Week/Module	Topic	Content and Activities
Week Prior to program		
	Staff Training (35 hours)	-Review manual/program -Assign tasks/roles (data collection, data input, facilitators) - Practice yoga, breathing, meditation - familiarize staff w/technology (Fitbit use) -Test equipment 3- breathing techniques 10- simple stretches & postures
Week One		
	- Caregiver support/education/training - Administer assessments - Data entry (Pre-test – Baseline data)	- Goal Attainment Scale (GAS) - Caregiver support/education/training - Review various breathing techniques - review postures - Practice partner yoga with trainers/facilitators
Week Two – Five		
	First weeks for all participants (5 caregiver-child dyads) Three stages of breathing (inhale, exhale, rest) , Smile Chanting w/ letter “E” ; Bubble Breathing, Straw Breathing (Bersma & Visscher, 2003; Goldberg, 2013) Addresses social determinants and support the improvements in culture for safety, health and wellbeing. Provides support for wellness with health (Social support model) Pre-mid-post testing w/Fitbit (every 15 minutes for HRV) Observations and recordings of dyad interactions e.g., number of and duration of smiles, gestures,	- 10-minute introduction/ roll dice game for topic of discussion - 10-15 minutes of breathing techniques “Belly Breath” and different sounds (e.g., vowels or animal sounds” - 20 minutes of yoga postures w/songs e.g., Butterfly Song, Seesaw Song to reinforcement movement pattern (Yoga Games for Children; Goldberg, 2013) - 5 minutes relaxation - 10-15 minutes of expressive art form e.g., Mandala, Drawing

	reciprocal interactions, cooperative play, engagement	
Weeks six – nine		
	<p>(5 caregiver-child dyads)</p> <p>-Add a new breathing technique “Cotton Ball on the Hand” new vowel or animal sound e.g., sound of snake...</p> <p>“Air Ball” Game during socialization</p> <p>- Pre-mid-post testing w/Fitbit</p> <p>Observations and recordings of dyad interactions and the amount and duration of behaviors (e.g., reciprocal interactions (sharing), smiles, gestures, and engagement.</p>	<ul style="list-style-type: none"> - 5- minute introduction w/music & new game (Yoga Games for Children; Goldberg, 2013) - Different parent-child dyad chosen to pick 1 new yoga pose card out of the four presented (www.KidsYogaStories.com) - 10- minutes of breathing techniques “Air Volley” & and 1 hand postures (Mudra’s) (Danzig, 2014) - 20 minutes of yoga postures (approx. 10 -12 simple partner poses) - 5 minutes relaxation - 10-15 minutes of expressive art form e.g., journaling, Mandal coloring <p>(HRV readings)</p>
Week Nine		
Last 20 minutes of the session	<p>Caregivers</p> <p>Post-tests (PSI-SF, COPM, GAS)</p> <p>Fitbit reading at the end of 30 minutes</p>	<p>Caregivers are in a separate room for 30 - minutes filling out forms and reviewing goals. Where goals attained from GAS?</p>
Follow- up	<p>Email PSI-SF & other Health Promotion evaluations</p> <p>Phone interview regarding carry over of skill</p>	

Appendix D: Evaluative Assessment Logic Model for the WE C.A.R.E. 2 Program



Appendix E: Fact Sheet

	<p>WE C.A.R.E 2 A parent-child community yoga program that promotes the health and well-being of caregivers and their children with autism spectrum disorder</p>	
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Introduction to Problem

- Increase in the prevalence of autism spectrum disorder (ASD) (Centers for Disease Control and Prevention, 2018)
- Caregiver's difficulty with symptomology and problematic behaviors e.g., aggression, hyperactivity
- Intensive behavioral interventions for children with ASD cost \$40,000 to \$60,000 per child per year
- High levels of stress among caregivers of children with autism
- Lack of education, support, and resources (Dunst et al, 2006)
- Lack of interventions and training in natural settings e.g., community, home (Kuhaneck et al, 2015)

Summary of the Program

The proposed nine-week parent-child yoga program, twice a week, will provide the knowledge, support, and skills to implement a community health promotion program to caregivers and their children with ASD (ages five to eight years). The core elements include:

- A training manual for facilitators and caregivers
- A week long (35-hour) yoga training session for facilitators (occupational therapy students) on techniques, movements, and adaptations to ensure the effectiveness of the yoga program
- A two-hour introduction for caregivers, e.g., symptomology, program, support, and practice
- 16 one-hour training sessions with dyads (caregivers/children), utilizing a multimodal learning approach, including hands-on practice with breathing techniques and mindful movement, to address the individual needs of participants
- Pre-post evaluations using five assessments to analyze behavioral and physiological changes
- Daily (pre-mid-post) readings of biomarkers, using real-time data e.g., heart rate variability (HRV) with Fitbit Charge
- A registered occupational therapist, director of the program, overseeing newly trained facilitators
- Three- month follow-up via phone for carryover of strategies

Introduction to the Solution: WE C.A.R.E 2 Parent-Child Yoga Program

This evidenced-based intervention (EBI) will provide:

- **Knowledge, support, and skills** to caregivers and their children with ASD
- Education, support, and training to **OT and OTA students (facilitators)** to increase the sustainability and effectiveness of evidence-based programs in the community
- More feasible, flexible, and accessible health promotion programs that foster the health and wellbeing of families e.g., stress management, emotional-regulation
- An individualized program that uses **modifications to adapt** to the needs of each participant and supports their own learning styles
- Opportunity to **apply skills to present level of "being"** and generalize techniques in their natural environments to further develop parent-child interactions and positive family relations
- Funding will be provided through grants and funding from gained partnerships e.g., universities, non-profit organizations

Yoga as a Therapeutic Tool

- Generally safe, flexible, and feasible for children and adults with ASD (Hourston & Atchley, 2017)
- One of the top ten complementary health approaches used by more than 13 million adults in the U.S
- Yoga has become more popular among children, just as it has among adults. 3.1% of U.S. children practiced yoga in 2012, compared to 2.3% in 2007
- More than 85 percent of U.S. adults who used yoga perceived reduced stress as a result of practicing yoga (Dunst, Trivette, & Cross, 2007)
- Helps improve general wellness by relieving stress, supporting good health habits, and improving mental/emotional health, sleep, and balance (National Center for Complementary and Integrative Health, 2016)



Occupational Therapy and Health Promotion

"As an inclusive profession, occupational therapy maximizes health, well-being, and quality of life for all people, populations, and communities through effective solutions that facilitate participation in everyday living" (AOTA, 2017). A few of those pillars that support and guide our profession are:

- Occupational therapy is influential in changing policies, environments, and complex systems
- Occupational therapy is evidence based, client centered, and cost-effective.

AOTA Vision 2025 aligns with the vision of Healthy People 2020 by creating a social and physical environment that promotes quality of life, healthy development, and healthy behaviors across all life spans.

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CURRICULUM VITAE

