

Respite and Well-being among Families with Children with Autism Spectrum Disorder

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ABSTRACT

RESPITE AND WELL-BEING AMONG FAMILIES WITH CHILDREN WITH AUTISM SPECTRUM DISORDER

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Parenting is a stressful endeavor that can be even more difficult for parents of individuals with Autism Spectrum Disorders (ASD). Autism Spectrum Disorder (ASD) has become increasingly prevalent over the past 15 years, which has baffled researchers and frustrated parents. Respite can be important to help alleviate stress for parents of individuals with ASD, and serve as a break for them from the demands of parenting. The present study utilized a mixed methods design to study the effect of respite on caregiver well-being. Using quantitative data, the study examined the effects of a respite cruise vacation organized by a travel group called Autism on the Seas on various indices of well-being among 20 parents of children with ASD. Parents provided survey responses prior to the cruise (pre-cruise measure) and three months after the cruise (post-cruise measure). Variables included caregiver stress, caregiver self-efficiency, caregiver social network and family quality of life. It was hypothesized that the Autism on the Seas respite vacation experience would be related to increased well-being among caregivers, specifically decreased caregiver reports of stress, increased caregiver reports of social network, increased caregiver reports of family quality of life, and increased caregiver report of self-efficacy. The quantitative study found significant associations among the well-being variables, however no statistical difference between the caregivers' reports of well-being on pre and post cruise measures. The qualitative component of the study aimed to describe perceptions of respite, barriers to respite-utilization, and aspects of respite that caregivers of children with ASD described as most beneficial. Six couples and one single father participated in the qualitative

component of the study. Interview transcriptions were all analyzed through open coding and then axial coding to find data trends and themes. It was hypothesized that respite would bring positive experiences to caregivers, allowing caregivers to take time to maintain their own well-being psychologically and physically. The qualitative study revealed the themes of the centrality of trusted caregivers to parent's willingness to accept respite, limited social networks of parent with children with ASD, and both caregiver well-being and child well-being and severity of ASD as important to parents' use of respite programs such that parents of children with more severe ASD reported more trouble accessing respite care. Together, the study points to the need for future studies to investigate a broad range of types of respite programs for individuals with ASD and their families.

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Chapter I

Introduction

The Research Problem

Parenting is a stressful endeavor that can be even more difficult for parents of individuals with Autism Spectrum Disorders (ASD) (Phelps, 2009). Autism Spectrum Disorder (ASD) has become increasingly prevalent over the past 15 years, which has baffled researchers and frustrated parents. In mid-November 2015, The National Health Statistics Report revealed an increase of ASD prevalence, suggesting that 1 in 45 children, ages 3 through 17, have ASD (Zablotsky, 2015). Respite is one tool which can be used to help alleviate stress for parents of individuals with ASD and serve as a break for them. Although new opportunities for respite have been introduced for caregivers of children with ASD, there is limited research that has examined the key components that comprise a beneficial respite for these caregivers. It is vital that more empirical studies be done to further identify factors associated with respite that are most effective at alleviating the stress of parents of children with ASD.

Study Rationale and Purpose

The health of caregivers of individuals with special needs is just as imperative as that of the individual with special needs. A caregiver must be physically and mentally healthy to effectively care for another individual. Past research states that caregivers of individuals with special needs are often stressed and have a low quality of life (Allik, et. al, 2009; Mugno et. al., 2007). Parents of children with ASD have been known to experience higher levels of stress than parents of children with any other condition (Phelps, 2009). Mothers of children with ASD have higher rates of mental health problems than other mothers in the community (Sawyer et al.,

2010). In addition, these parents' highest stress pertains to family social activities, personal social activities, and their relationship with their partner (Phelps, 2009). Past research supports that families of children with developmental disabilities participate in fewer family interactions and recreational activities than families who do not have a child with ASD (Phelps, 2009; Sawyer et al. 2010). Despite the relevance of respite in regard to the above-mentioned problem, little research has been done on this topic. Respite care is a type of support that refers to a service provided when another individual assumes the role of caregiver for the individual with special needs for short periods of time (Chan & Sigafos, 2001; Meadan et al., 2010).

Autism on the Seas is an organization that provides respite services to accommodate families with children with ASD and other special needs during a vacation. The organization provides respite sessions for caregivers to drop off their child with special needs with professional staff. Using a sample of past Autism on the Seas cruisers, the purpose of the current research study was twofold. First, the study aimed to assess several indices of caregivers' psychosocial well-being and how respite was related to each of these factors. A comparison between pre-cruise and post-cruise data was also analyzed in order to see if caregivers reported any change in their psychosocial well-being after participating in the Autism on the Seas vacation experience. An understanding of individual differences in caregiver well-being and experiences with respite will help the field to begin to provide more effective resources to support those caregivers with the greatest need. This component of the study elicited caregivers' self-reported responses to a questionnaire designed to measure their psychosocial well-being and respite experiences.

The second aim of the study was to explore both mothers' and fathers' perceptions of the key components of respite, barriers associated with effective respite, and the perceived benefits

of respite. To address this aim, this component of the study utilized qualitative interviews with caregivers of individuals with special needs to understand common themes that emerge on the topic of respite for these parents. Data from these interviews will inform the design of more effective respite programs and this aspect of the study will allow us to fill a gap in the limited research on respite by incorporating the perspective of caregivers, the members of the family who are most affected by respite services. Previous research has argued that the perceptions and experiences of fathers is often neglected, the current study will incorporate this perspective (Robertson et al., 2011).

As will be discussed in detail below, the current study was guided by the ABCX framework on caregiver well-being which emphasizes the role of resources and supports on the family's response to a stressor (Hill, 1958, p. 143). The ABCX framework can be applied with consideration that the moderating variable between stress and disability is respite. In line with this conceptualization, it may be that providing effective stress management supports, such as respite for caregivers of children with ASD, may lead to a decrease in stress and thus a healthier life both physically and psychologically for these individuals.

Chapter II

Review of Literature

Chapter II provides a review of the current literature on respite. The chapter introduces a brief overview of three theoretical frameworks that have helped frame this research study. These theories include Bronfenbrenner's Ecological Theory, ABCX Theory, and Family Stress Theory (Bronfenbrenner, 1996; Hill, 1958, p. 143; Perry 1989). The chapter then describes the indices of caregiver well-being that were addressed in the study including caregiver stress, caregiver family quality of life, and caregiver self-efficacy. The chapter concludes with a rationale for the current study, and the research questions being examined.

Bronfenbrenner Ecological Theory

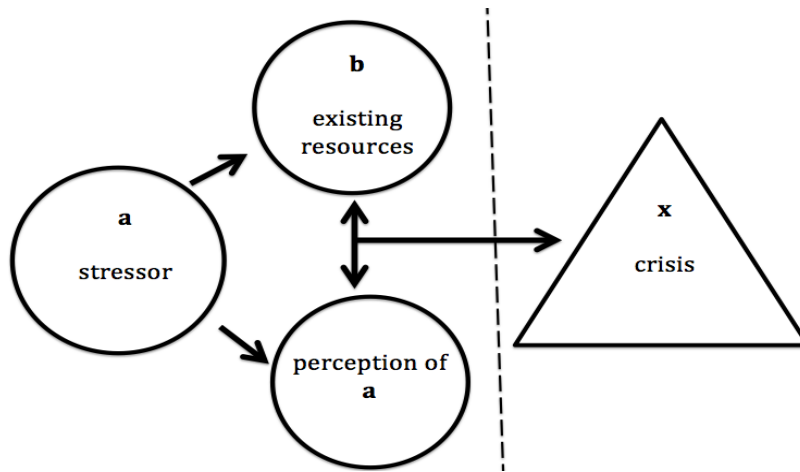
The Ecological Systems theory highlights the impact of environment on children's development (Bronfenbrenner & Crouter, 1983). Within the paradigm, three different environmental systems were described that serve as sources of external influence on the family (Bronfenbrenner & Crouter, 1983). Mesosystems (e.g., situations within the family), ecosystems (e.g., family social network), and chronosystems (e.g., developmental transitions) were all contexts that played significant roles in shaping development. This model emphasized the strong role parents play in their children's development. Caregivers and their children are influenced by one another and the psychological development of both individuals are interconnected. Such work highlights the importance of focusing on the parents of children with ASD, and of examining factors linked to a service designed to provide relief to caregivers to improve their well-being, which may ultimately have a positive impact on children's development.

ABCX Model

The ABCX Model explains “the crisis-proneness and freedom from crisis among families” (Angell, 1936; Cavan & Ranck, 1938; Hill, 1958, p. 143; Reuben Hill, 1949, 195). This model is now the basis of most family stress models and can be applicable to families of children with special needs. The ABCX Model emphasizes the pre-crisis factors influencing families: *A* (the crisis-precipitating event/stressor) interacting with *B* (the family’s crisis- response) interacting with *C* (the definition the family makes of the event) and the outcome that these factors produce *X* (the crisis).

With consideration to the field of special education, the current study applies this model to families of children with ASD. As seen in Figure 1, *A* may be considered the ASD diagnosis along with the behavioral and communication challenges of the child with disabilities, *B* may be considered respite as a service and resource to families, *C* may be considered the family’s perception of the child’s disability, and finally, *X* may be the caregiver’s psychosocial wellbeing (e.g., stress). Respite may provide more benefits to the family than just time off from caregiving. When socializing with families with similar profiles, caregivers may be more likely to have a more positive perception of disability. Associating with similar caregivers may provide social support to these individuals or de-stigmatize them, causing a more positive perception of disability. Thus, respite services (*B*) could lead to a change in the perception of disability (*C*) which leads to reduced caregiver stress and may even prevent future crisis.

Figure 1. ABCX Model
Reuben Hill's ABCX Model.



Family Stress Theory

The family stress theory has been strongly influenced by five other theories including; family systems theory as applied to families of children with developmental disabilities (e.g., Turnbull, Summers, & Brotherson, 1986), ecological theory (Bronfenbrenner, 1979), social support theory (Cohen & Syme, 1985), sociological family stress theory (McCubbin & McCubbin, 1987), coping theory (Folkman, Schaefer, & Lazarus, 1979), and developmental psychopathology (Cicchetti & Lynch, 1993). The family stress theory (Perry, 1989) elaborates off of the ABCX theory. This theory is more in depth than variations of the ABCX theory because it defines four different conceptualizations of stress. First stress is defined as a psychological or physiological response of the body (Selye, 1980). When looking at families with children with ASD, the model implies that stress is not simply a function of child characteristics (stressors) but is more than a single stressful life event or even a series of daily hassles. The model states that the stress depends on the individual parent's coping abilities, the resources in the family, and the supports the family receives from others. Factors such as coping

strategies and social support may act as moderating variables interacting on crisis outcome(e.g., Dunn, Burbine, Bowers, & Tanteleff-Dunn, 2001; Hastings & Johnson, 2001).

Using Family Stress theory to structure this study, I examined respite, a resource for caregivers and its impact on various factors of caregiver well-being. The family stress model takes child characteristics, other life stressors, individual's personal resources, family system resources, informal social support, formal supports and services, negative parental outcomes, and positive parent outcomes into account when predicting the crisis outcome. The model utilized in the current study places a higher emphasis on the family resource piece. The quantitative aspect of the study investigates specific fine-tuned caregiver perspectives with regards to respite utilization and other coping strategies. The qualitative study focuses on what resources families with children with special needs report as the most effective for maintaining their psychosocial well-being.

Indices of Well-Being Among Caregivers of Children with ASD

Caregiver Stress. Parents of children with ASD have been known to experience higher levels of stress than parents of children with any other condition and parents report that ASD affected each area of their lives: psychological, family, social, services, spiritual benefits, economic challenges, and future orientation (Phelps, 2009). Parents of children with ASD have been reported to make extreme sacrifices with respect to their children (McCabe, 2007). Sacrifices include spending less time with family and friends and not being employed full time. Higher levels of parenting stress for parents of children with ASD were found when compared to stress of parents of children with Down syndrome and parents with other disabilities (Benson, 2009). The severity of the child's ASD symptoms and problematic behaviors has consistently been found to be a strong predictor of parental stress.

Stress proliferation is defined as a tendency for stressors to create additional stressors, is an important contributor to other mental health problems, including depression, among caregivers for children with ASD (Benson, 2009). Factors associated with the increase risk for mental health problems among parents with children with ASD included: level of childhood behavior problems, gender (mothers have higher risk than fathers) and age of the parents (older parents have a higher risk than younger parents); level of parental social support and parental psychological characteristics, such as perceived self-efficacy, and locus of control and coping style (Sawyer et al., 2010). Additionally, the study found that diagnostic postponement, difficulty dealing with ASD problem behaviors, and lack of social networks and leisure activities were the factors associated with the higher stress levels of caregivers for individuals with ASD.

Demanding responsibilities for caregivers contribute to caregiver strain (Phelps, 2009). Parents who report more strain tend to be those who report caring for a child with aggressive behaviors and extreme dependence on the caregiver, or the child whose attachment and affection are not expressed in the way's parents might have anticipated. It has been shown that mothers experience greater instances of stress or strain related to daily exposure to problems when compared to fathers of children with ASD (Falk, 2014). The inability of parents to manage or alter negative behaviors may lead to increased stress and hindered psychosocial well-being (Estes et al. 2009; Griffith et al. 2010; Hamlyn-Wright et al. 2007; Kasari & Sigman 1997; Wolf et al. 1989). These findings may provide insightful information to caregivers of individuals with ASD and practitioners providing services to them. Importantly, the highest stress pertains to family social activities, personal social activities, and parents' relationship with their partner (Phelps, 2009).

High levels of parenting stress have been shown to correspond with less optimal parenting behaviors such as low caregiver self-efficacy, and failure to engage in services (Hassall, Rose, & McDonald, 2005; Hastings & Johnson, 2001; Tomanik, Harris, & Hawkins, 2004). These less optimal parenting behaviors lead to less beneficial outcomes for children in early intervention programs, decisions to seek out-of-home care for their child, impeded child development, and higher rates of child psychopathology and antisocial behavior (Brinker, Seifer, & Sameroff, 1994; Llewellyn, McConnell, Thompson, & Whybrow, 2005; O'Connor, 2002). Interventions such as the one presented in the current research may alleviate some of this parenting stress, and thus lead to more favorable outcomes for these individuals with ASD.

Past research supports that families of children with developmental disabilities participate in fewer family interactions and recreational activities than families who do not have a child with ASD (Folkman, & Lazarus, 1985). In the current research, the context of family social activities via respite was targeted. Respite activities may be a way of reducing some of the highest levels of parent stress. Themes generated by qualitative interviews suggest that formal social supports were helpful by allowing the family to pursue activities together and overall supported the family in further understanding their child (Phelps, 2009). Interviews have also found that families believed that their child was an integral part of the family but needed support in adjusting outings to accommodate the entire family. High levels of parenting stress are associated with poor interventional outcomes in regard to treatment of children with ASD (Bhagat, Jayaraj, & Haques, 2005). Respite was observed as a factor that decreased hospitalizations for children with ASD. The research provided evidence that respite interventions reduce parenting stress and can benefit the children with ASD and also, the family as a whole.

Family Quality of Life. Quality of Life (QOL) has been defined by the World

Health Organization as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a multidimensional concept which incorporates the individual's perception of these and other aspects of life. Family quality of life surrounding an individual with special needs has become an increasingly interesting topic of research (Aznar & Castañón, 2005; Turnbull, Brown, & Turnbull, 2004). It is not a surprise that a disability not only affects the person with a diagnosis but, in many cases, the broader family's quality of life may be even more significantly impacted.

Parents of children with Pervasive Developmental Disorders (PDD, now referred to as ASD) showed a significant impairment of QOL as compared to the other groups (Mugno et. al., 2007). While parents of children with developmental disabilities accommodated to their child's needs early on, for example, by restricting their social life and making changes in family routines, their health-related quality of life (Larsson & Smedge, 2009) was negatively impacted with a child with ASD (Allik, Larsson, & Smedge, 2009). Quality of life research focuses on the interaction between an individual and the environment, and specifically explores individual well-being by examining such factors as family situation, social supports, leisure activities, spiritual values, career opportunities, and economics (Brown, Bayer & Brown, 1992). Quality of life is defined by how an individual interprets the environment and how various factors affect his/her well-being. Because quality of life is up to interpretation (Schalock et al., 2001), it is consequently a factor that is only accountable for by self-report. It was found that families without a disability had much greater satisfaction scores in multiple domains when compared to families with disability with respect to quality of life (Brown et. al, 2006). When studying the quality of life of parents of children with disability to identify the factors associated with the

parents' psychological adjustment, it was found that social support is a critical factor that reduces the negative psychological effects of raising a child with PDD and that consequently contributes to successful adjustment (Cape et. al, 2011).

Studies have found that parents of children with ASD may be less physically and mentally healthy than parents of other children. Significantly lower physical health summary component scores and mental health component scores than parents of typically developing children on the Medical Outcomes Study (MOS) 36-item short form health survey were reported (Lee et. al, 2009; Ware & Sherbourne, 1992). Mothers reported poorer physical health after measured by the 12-item Short Form Health Survey (SF-12) (Ware, Kosinski, & Keller, 1996), than the control group mothers of typically developing children or the fathers of the children with Aspergers (Allik, Larsson & Smedge, 2006).

Research regarding services and inventions are imperative to improve family quality of life (e.g., Bailey et al., 1998; Dunst & Bruder, 2002; McKenzie, 1999; Hoffman, et. al., 2006). A review of studies that empirically tested the effects of interventions targeting improvements in the mental health of parents of children with ASD revealed that treatment produced medium to large effect sizes on average with improvements in parenting stress and general health, and reductions in depression and anxiety (De Paz & Wallander, 2017). Effective interventions included: Stress Management and Relaxation Techniques, Expressive Writing, Mindfulness-Based Stress Reduction, and Acceptance and Commitment Therapy. A quasi-experiment examining the effectiveness of brief mindfulness- based interventions on perceived quality of life and positive stress appraisals among caregivers of children with ASD found that after the intervention program, parents in the intervention group demonstrated significant improvements in measures of psychological health domain of QOL, social health domain of QOL, mindfulness,

and positive stress reappraisal with medium to large effect size (Rayan & Ahmad, 2016). Skillful intervention is related to a meaningful increase family quality of life for a caregiver with a child with ASD (De Paz & Wallander, 2017; Rayan & Ahmad, 2016).

Caregiver Social Network. One factor that is related to reduced parental stress is social support (Bristol, 1984; Dyson, 1997; Sharpley, Bitsika, & Efremidis, 1997). Social support is defined as a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support (Boyd, 2002; Dunst, Trivette, & Cross, 1986). There are multiple studies that report a lack of social support for caregivers with ASD.

A study examining the stress and adjustment of parents via interviewing 54 families whose children had varying disabilities revealed that mothers of children with ASD reported more family and parent problems, a higher pessimism factor with regards to the potential of their child being self-sufficient, and more perceived negative child characteristics when compared to parents of children with down syndrome, or typically developing children (Sanders & Morgan, 1997). These caregivers also reported less family participation in recreational activities than caregivers of typically developing children (Boyd, 2002). A study examined stress and adjustment in three groups of families, caregivers caring for an individual with autism, caregivers caring for an individual with Down syndrome, and caregivers of typically developing children (Sanders & Morgan, 1997). A lack of social support can lead parents to withdraw from the larger community because of the negative characteristics they associate with their child's disability (Sanders & Morgan, 1997). This study also found that caregivers of individuals with ASD had the most difficulty obtaining community-based social support when compared with caregivers of typically developing individuals.

In a study examining the consequences of a lack of social support on mothers and fathers, 172 parents of children with autism provided their reports on their children's health and treatment status and coping behaviors in terms of their effect on parental depression, anxiety, and anger (Gray & Holden, 1992). The study showed that parents who received more social support scored lower on measures of depression, anxiety, and anger. Mothers who received less social support were also angrier (Gray & Holden, 1992).

A study investigated the social support provided by spouses of parents of children with ASD (Konstantareas and Homatidis, 1989). It should be noted that there were 24 mothers, and only 3 fathers in the study. The study revealed that specifically, mothers wanted the husband to (a) provide them with some relief from caring for the child with ASD, (b) play more of a part in disciplining the child, and (c) provide help spontaneously with daily chores, instead of having to be asked (Konstantareas & Homatidis, 1989). The study also revealed gender differences, such that mothers were more aggravated with support agencies than fathers, and mothers' ratings of the severity of the disability were closer to the clinical ratings than the fathers.

Although children with ASD may cause significant strain on the marital relationship, contrary to past notions of higher rates of divorce among families with special needs, recent work reveals that parents of children with ASD are no more likely to separate or divorce than other parents, and they may be more reliant on support from their parenting partnership because they often experience a sense of isolation and a loss of support from family and friends (Brobst, Klopton, & Hendrick, 2009; Freedman, Kalb, Labotsky, & Stuart, 2012; Gray, 1997, 2003; Woodgate, Ateah, & Secco, 2008). A lack of social support can lead parents to withdraw from the larger community because of the negative characteristics they associate with their child's disability—which in turn elevates their stress level (Sanders & Morgan, 1997). The present

study ensures that both mothers and fathers are interviewed to reveal perspectives on the two parenting roles and to provide a more well-rounded portrayal of a caregiver's life with ASD.

Caregiver Self-Efficacy. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave (Bandura, 1994). Parenting self-efficacy is a multidimensional concept defined as parental beliefs or confidence in their ability to successfully carry out parenting tasks and is a distinct, domain-specific concept captured under self-efficacy theory (Vance & Brandon, 2017). Studies have revealed that parental stress and mental health issues are negatively associated with parenting self-efficacy, or parents' perceived feelings of competence in the parenting role (Coleman & Karraker, 1998; Cutrona & Troutman, 1986; Kuhn & Carter, 2006; Scheel & Rieckmann, 1998; Teti, O'Connell, & Reiner, 1996).

For parents to employ parenting behavior successfully, they must both believe that it will produce the desired outcome and have confidence in performing the specific behavior (Bandura, 1997; Salonen et al., 2009). Parental self-efficacy can be broken down into four categories; (a) parents' personal beliefs, (b) what a parent can do under a set of conditions with their capabilities, (c) a set of organized actions to produce a set of tasks under difficult circumstances, and (d) a situation-specific tasks (Bandura, 1997). A review of self-efficacy, suggest that parenting self-efficacy impacts child adjustment directly but is indirect in its effect on parenting practices and behaviors (Jones & Prinz, 2005). Parenting self-efficacy is imperative for caregivers' sense of well-being, and may be a possible predictor of parenting practices and indicator of risk of depression (Salonen et al., 2009).

A model which described the interaction between parenting efficacy beliefs, promotive parenting strategies, and child's success was developed using a large sample of 376 mothers and their adolescent children (Ardelt & Eccles, 2001). It was found that that parents who are high in

parenting self-efficacy are more likely to be engaged in parenting practices that promote positive child adjustment, increasing the likelihood for their child's success in both academic and social-psychological domains. The tested model also identified a reverse effect. Parents faced with difficult child behavior problems may find it difficult to maintain high parenting efficacy beliefs resulting in less promotive parenting behaviors. Their data was consistent with the view that observing successful outcomes in their child might strengthen parenting self-efficacy.

There have also been multiple studies which examined parenting characteristics of mothers with high and low self-efficacy and their relationships with child outcomes and parental psychological health. Low maternal efficacy has been correlated with maternal depression (Bandura, 1997; Teti & Gelfand, 1991), maternal perceptions of child difficulty (Johnston & Mash, 1989), high levels of parenting stress, parental negative affect, elevated autonomic arousal, and feelings of helplessness and frustration in the parenting role (Coleman & Karraker, 1997; Jones & Prinz, 2005).

Low parent self-efficacy is associated with the parent's increased focus on parent-child relationship difficulties, negative affect, feelings of helplessness in the parenting role, and use of coercive disciplinary techniques (Bugental et al., 1989). The relationship between parenting self-efficacy and various parent variables was investigated in a sample of 170 mothers of children with ASD (mean age 6.5 years of age) (Kuhn & Carter, 2006). These parent variables included mothers' cognitions such as depression, parenting stress, maternal agency, guilt, and ASD knowledge among mothers of children with ASD. Parenting self-efficacy to be inversely related to levels of parental stress and depression in mothers of children with ASD. Thus, self-efficacy was positively correlated with maternal sense of agency (engaging in activities to promote her child's development) and negatively correlated with maternal sense of guilt.

Respite interventions have been shown to be correlated with increased self-efficacy. One study found that when parents receive respite, their stress levels are reduced and they feel that they have more support and resources (Keen, Couzens, Muspratt & Rodger, 2010). The current study investigates a specific respite program designed for parents of children with ASD and its effect on self-efficacy.

Respite Services

Respite care is a type of support that refers to a service provided when another individual assumes the role of caregiver for the individual with special needs for short periods of time (Chan & Sigafos, 2001; Meadan et al., 2010). Respite care is discussed as not only a break option for caregivers who experience stress and need relief, but also as providing opportunities for children with special needs to interact with peers, to achieve independence, and experience relationships outside of their family circle (Merriman & Canavan, 2007). Respite is described as “planned care for the child with autism to provide relief to the permanent caregiver” (Harper et al., 2013) However, the definition of respite has evolved, and respite has been known to improve the caregiving capacity of caregivers (Merriman & Canavan, 2007).

A review of literature concerning the outcomes of respite interventions for individuals with ASD aimed to investigate best practice in respite care for people with intellectual disability and autism and to provide a resource for raising the policy profile of respite care and provide support for further research (Merriman & Canavan, 2007). The study was a combination of a focused review of literature and consultation with stakeholders including service providers, academics in the policy field and caregivers of individuals with intellectual disabilities and autism. The study started by defining the different forms of respite care, these included: informal help from family and friends, formal respite care in the service user’s home, out of

home respite facilities and recreation and holiday breaks. The results of the research study concluded in identifying a number of principles of best practice with regards to respite. These include: respite services should be person-centered and family centered; respite services should be provided on a rights basis; respite should be defined as a support service and regarded among a system of support services; there should be a single point of access to respite care services in a given administrative area; respite services should be designed in consultation with families in acknowledgement of their expertise in providing care; respite should be designed to facilitate the service user in building relationships in their community; respite services should be age-appropriate and develop as the service user develops; and respite services should have clear goals and that systematic and regular review ensure achievement of these goals (Merriman & Canavan, 2007).

An evaluation of respite child care programs through group comparisons of matched pre and post test Parenting Stress Index scores determined that life stress, social support, and service level were significantly related to the occurrence of child maltreatment during the utilization of respite services (Cowen & Reed, 2002). In this study, sociodemographic characteristics, parenting stress levels, foster care placement, and child maltreatment rates were assessed in families of children with developmental disabilities who were utilizing respite care services. Significant reductions in stress levels after all respite utilization were reported (Cowen & Reed, 2002).

Through a quasi-experimental follow-up analysis with 46 primary family caregivers of children with intellectual disability, another study assessed mental health outcomes among children with intellectual disability and their families who were receiving home-based care (Shu, Lung & Huang, 2002). Parents were asked to complete a 12-item Chinese Health Questionnaire,

which was used to evaluate each participant's mental health at three time points (baseline, 3 months, and 9 months). Improvements in psychological well-being were found (Shu, Lung, & Huang, 2002). The study provided home care services to the children with special needs by a team of multidisciplinary health care professionals (Shu, Lung & Huang, 2002). Services provided during visits to included; providing direct care to the children with ID; assisting and teaching primary caregivers to solve daily care problems; guiding these caregivers on how to access and utilize community resources, and how to seek community social support; and providing services by telephone when the need arose. These visits were made routinely. Caregivers were "refreshed and "better able to face the challenges of full-time care." Additionally, caregivers self-esteem was improved by respite care utilization (Cotterill et al., 1997). Positive effects on family functioning were also found from multiple studies (Chan & Sigafos, 2001; Cotterill et al., 1997; MacDonald & Callery, 2004). These findings are in line with those from a literature review focused on variables that predicted use versus non-use of respite with families with children with special needs (Chan, Sigafos, 2011). The more often families made use of respite care, the lower their scores on measures of perceived family conflict (Chan & Sigafos, 2001)

Respite has been used to give families a chance to "rest," "refresh," relax," "refocus," "regroup," and "recharge" (Doig et al., 2009). Respite helps families to live "a more ordinary life" (Robinson et. al, 2011). Respite has also been shown to have a positive effect on siblings, possibly because it increases marital quality and allows parents time to spend with their other children (Langer et al. 2010; Welch et al. 2012). In one study, data was collected from 239 caregivers of both a child with special needs and a typical developing child (Welch et al. 2012). The results of the qualitative analysis of data revealed that short breaks have the potential to

alleviate some of the negative impacts of being a sibling in a family with special needs. Respite care has also been reported to benefit marriage (Stalker, 1988; Stalker & Robinson, 1994). Both studies analyzed qualitative semi-structured interviews, there was no intervention involved. In a study where 101 mother-father dyads of children with ASD responded to a questionnaire, the authors found that the number of hours of respite care was positively related to better marital quality for both husbands and wives (Harper et al., 2013). This research found that a one-hour increase in respite care was associated with a one-half standard deviation increase in marital quality.

Holiday breaks were studied as a respite option (McConkey & McCullough, 2006). The researchers examined the Daisychain Foundation which offers complimentary two-night breaks at hotels to caregivers and other family members of people with intellectual disabilities, physical disabilities, and autism (Daisychain Foundation, 2006). Two hundred and nine questionnaires were collected surveying caregiver feedback with regards to the respite holiday option.

Depending on the family, the individual with ASD can join them at the hotel or respite care can be arranged, no staff or facilities were available at the hotel. Benefits reported by users include new experiences and activities, spending time with and meeting new friends, having fun, and getting away from home. These caregivers were reported to have increased self-confidence, improved communication and decision-making skills and generally a better quality of life as assessed after one two-day holiday (McConkey & McCullough, 2006).

A literature review on the relationship between parenting stress and the lack of social supports for mothers of children with ASD discussed three self-report instruments commonly used to measure the magnitude of stress experienced by parents of children ASD, and the social supports (formal or informal) available to them (Boyd, 2002). The literature review revealed an

association between challenging child characteristics and a mother's inclination to seek social support, with mothers under greater stress being more prone to pursue social support. This study reviewed research from professional peer-reviewed journals and two edited books concerning the use of social support to alleviate stress in mothers of children with autism. In the study, informal support appeared to be a more effective stress-buffer than formal support. Finally, the results of multiple studies showed that parents who received support related better emotionally to their children. These results were assessed through the Parenting Stress Index (PSI; Avidin, 1983), the Questionnaire on Resources and Stress (QRS; Holyroyd, 1974), and Family Support Scale (Dunst, Jenkins, & Trivette, 1984). Thus, low levels of social support were the most powerful predictors of depression and anxiety in mothers. Additionally, spouses provided the best informal source of support by providing respite for one another, dividing the responsibilities of household management, and sharing the role of disciplinarian (Boyd, 2002).

There are few intervention studies on the effects on parents and children of providing respite care to families with children with developmental disabilities . A review of the studies concluded that families who utilized respite services experienced a decrease in stress levels and were better able to cope with caring for a child with special needs, when compared to families who did not utilize respite services (Chan & Sigafos, 2001). It should be noted that the review did not report the methodological quality of the studies reviewed. In a longitudinal study, a respite group was compared to a group of parents with children who were admitted for a 30-day inpatient treatment (Mullins, et. al 2002). The Brief Symptom Inventory and the Parenting Stress Index were used at time of inpatient admission, discharge and a 6 month follow-up. Results showed that there was significantly lower psychological distress levels at discharge, and 6 month follow up for both groups (Mullins, et. al 2002). Parenting stress was also significantly

lower at time of discharge but at the 6 month follow up, distress levels had increased back to levels at admission time. Psychological distress levels in the respite group were comparable to that of the long stay (Mullins, et. al 2002).

Unfortunately, parents report that children with ASD have less access to recreation and leisure services because of the demands related to having a child with ASD and thus parents are given less “off” time (Sanders & Morgan, 1997). Indeed, data from a national survey of children’s health showed that parents of children with ASD not only have more caregiving burden and limits on family and community activities but are also more likely to quit their jobs due to childcare problems than parents of children with attention deficit disorder/ attention deficit hyperactivity disorder or parents of typically developing children (Lee et al., 2008).

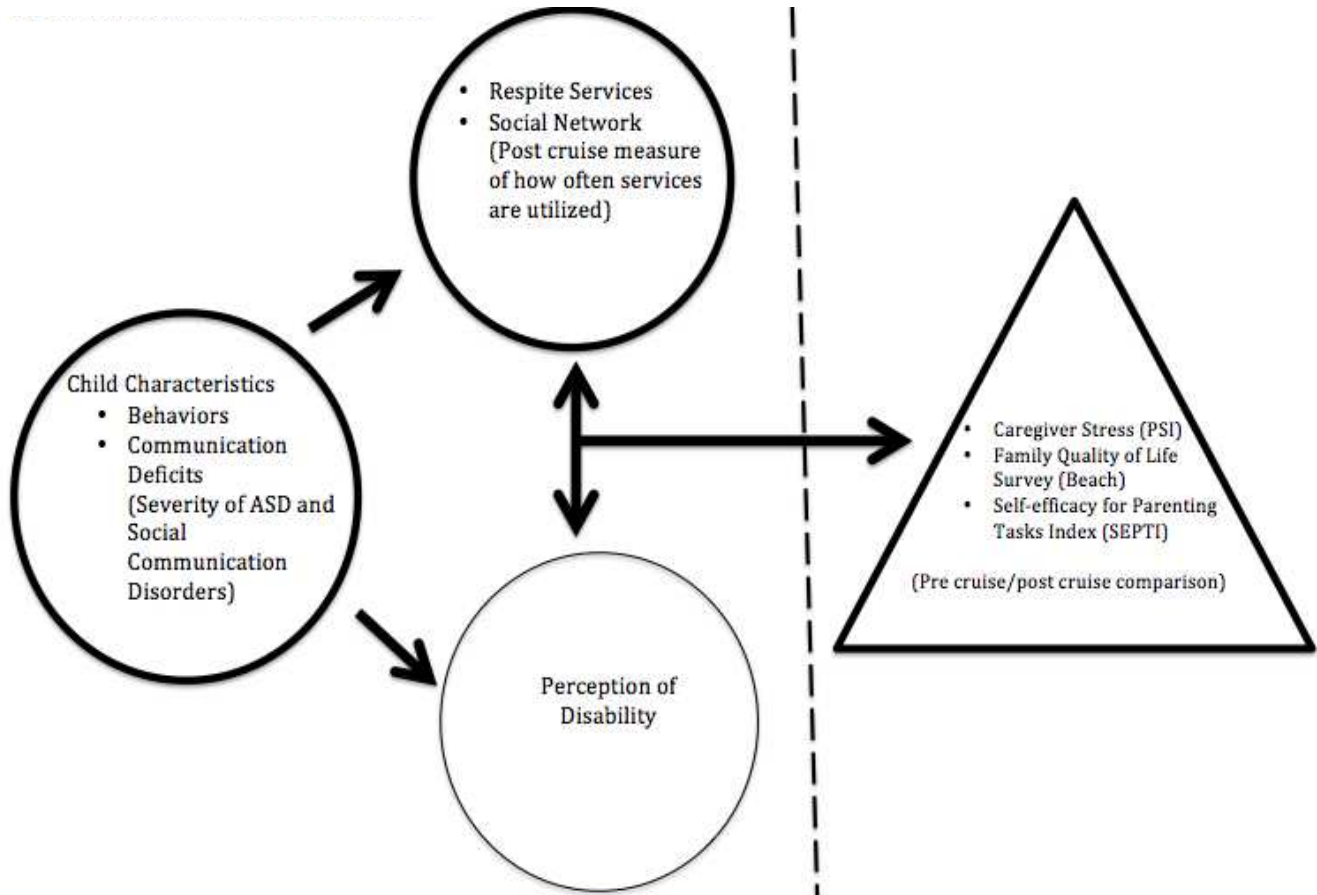
The relationship between respite care, depression, stress, and uplifts (i.e., positive feelings) was studied across 122 single mothers of children with ASD (Dyches et. al., 2016). Four measures were administered each one time in this study, including the Center for Epidemiological Studies Depression Scale (CES-D; Radloff 1977), the Caregiver Burden Instrument, an adaptation from Robinson (1983), the Hassles and Uplifts Scale (HUS; Lazarus and Folkman 1984), and the Respite Care Questionnaire. Findings supported that a significant positive relationship between the amount of respite care and daily uplifts was found in addition to daily uplifts being a mediator between the amount of respite care and depression. In other words, the utilization of respite services was associated with an increase in positive feelings and decrease in depression.

There are clear benefits associated with respite for families of children with ASD and other disabilities. However, there is a critical need for more information to better understand the critical components of respite in an effort to design the most accessible and effective resource for

these families. Past work also supports the notion that perspectives on respite and family well-being may differ among family members, and that researchers should incorporate multiple perspectives in future research. In particular, research on varying perceptions with regards to respite between fathers and mothers remains an understudied area (Robertson et al., 2011). The present study aims to extend this past work by examining caregiver stress, caregiver self-efficacy, family quality of life and caregiver social network in a sample of families who participated in a respite service called Autism on the Seas. Autism on the Seas is an organization that provides services to accommodate families with children with ASD and other special needs during a vacation. Autism on the Seas staffed cruises are selected from the regular cruiseline schedule throughout the year and assists adults and families by accommodating the typical cruise services, as well as providing specialized Respite and Private Activities/Sessions that allow guests the use of the ship's entertainment venues in an accommodated and assisted manner. Families pay a fee in addition to the cruise price for Autism on the Seas services. Professional Staff (educated, experienced, background checked and sanctioned by the cruise lines) accompany the families on the cruise to provide these supportive vacation and travel experiences onboard cruise ships. These professionals volunteer their time and services in exchange for a free cruise. In addition to cruising with professional staff, families also cruise with other families with individuals with special needs. The group serves as a strong support system for one another.

Figure 2. Conceptual Model

ABCX informs the current work, but in this present study only ABX is being evaluated.
B (resources) respite services and social support



Summary and Rationale

Although new programs, like Autism on the Seas, have been designed to assist with respite and stress management for caregivers with ASD in the context of family outings and vacations, it is vital to understand the key factors that impact parents' experiences with these and other programs. Specifically, there is a need to understand how such programs are related to parents' psychosocial well-being and whether parents experience any barriers or other limitations

engaging in these programs. Such information would help inform the design of more accessible and effective respite programs. The present study had the following aims and research questions.

Study Aim 1

The first aim of the study was to investigate factors associated with parent well-being among caregivers who participated in a respite vacation program. Quantitative methods were used to assess study variables.

Research Question 1. Was there a relationship between caregiver-reported parenting stress, perceptions of the supportiveness of the social network, family quality of life, and self-efficacy when controlling for parent-reported child severity of disability? *It was hypothesized that with increased stress, there would be a decrease in caregivers' reports of social network, lower family quality of life and lower caregiver self-efficacy.*

Research Question 2. Was there a stronger association between respite and family outcomes for families of children with more severe disabilities?

2a. Was there a stronger negative association between respite and stress for families of children with more severe disabilities?

2b. Was there a stronger positive association between respite and family QoL for families of children with more severe disabilities?

2c. Was there a stronger association between respite and social network for families of children with more severe disabilities?

2d. Was there a stronger association between respite and self-efficacy for families of children with more severe disabilities?

It was hypothesized that the positive association between respite and family well-being will be stronger for families of children with more severe disabilities.

Research Question 3. Was there a difference in caregivers' reports of well-being three months after their sailing on the Autism on the Seas respite vacation in comparison to pre-cruise reports when controlling for child characteristics?

3a. Was there a decrease in caregivers' reports of stress after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver stress prior to the vacation when controlling for child severity? *Although vacations can themselves be stressful, it was hypothesized that the Autism on the Seas respite vacation would decrease caregivers' reports of stress because it would give caregivers time off to refresh themselves, and give them hope for future vacations.*

3b. Was there an increase in caregivers' reports of their social network after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver social network prior to the vacation when controlling for child severity? *During these respite vacations, families often stay in touch with other families they meet during the week, and serve as a source of emotional support for one another. Often this bond lasts for longer than the duration of the cruise, thus it was hypothesized that there would be an increase in caregivers' reports of social network.*

3c. Was there an increase in caregivers' reports of family quality of life after experiencing the Autism on the Seas respite vacation as compared to their reports of family quality of life prior to the vacation when controlling for child severity? *It was hypothesized that there will be an increase in caregivers' reports of family quality of life after the respite vacation because they will have a good vacation experience to look back on and the hope of planning similar vacations bonding the family.*

3d. Was there an increase in caregivers' reports of self-efficacy after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver self-efficacy prior to the vacation when controlling for child severity? *During the Autism on the Seas respite vacations, professional staff work with the individuals with special needs in front of the caregivers. It was hypothesized that there will be an increase in caregivers' reports of self-efficacy because caregivers will learn more strategies in working with their child from professional staff.*

It was hypothesized that the utilization of respite would be related to decreases in parent reports of negative psychosocial factors (stress) and increases in positive psychosocial factors (family quality of life, caregiver self-efficacy, and caregiver social network) when controlling for child severity as compared with pre-cruise reports. Thus, respite utilization would be associated with decreased caregiver stress levels and increased caregiver social network, increased respite utilization, increased family quality of life; and increased caregiver self-efficacy when controlling for child severity.

Study Aim 2

The second research study aimed to identify the barriers and components of respite that were most beneficial to caregivers, their perceptions on respite, and the varying perspectives of husbands and wives using qualitative research methodology. The study posed the following research questions:

Research Question 1. How did caregivers of children with ASD describe the association between respite and their well-being?

Research Question 2. What did caregivers describe as the key components and barriers of respite?

Research Question 3. How did caregivers' perceptions of respite vary between husbands and wives?

Research Question 4. What did caregivers perceive as the benefits of respite for individuals with ASD?

Chapter III

Method

The current study employed a mixed method design and was comprised of two studies. Study 1 used a quantitative research design and Study 2 used a qualitative research design. By utilizing a mixed methods design, the researcher was able to gain an in-depth understanding of respite and its utilization. Triangulation was used to identify aspects of respite more accurately by approaching it from different vantage points using varying methods. The weaknesses of both quantitative and qualitative studies are often offset when a mixed methods design is employed.

Research Design: Study 1

Study 1 used a quantitative research design. This study sampled a population of caregivers with children with ASD to understand individual differences in caregivers' reports of well-being and compare pre and post data after a respite vacation. Data analyses were comprised of correlations (Pearson or Spearman, depending on data level of measurement) and repeated measures ANCOVA analyses.

Participants: Study 1

Demographics of all participants were self-reported. Within Study 1, there were two sub-samples. The first sub-sample ($n=96$) consisted of all caregivers who completed the post cruise survey. This sample was used to test hypotheses about associations among study variables. The second sub-sample ($n=16$) consisted of only the caregivers who completed both pre and post-cruise surveys. This sample was used to test hypotheses about the effect of the Autism on the Seas intervention on parent and family wellbeing (i.e., from pre-cruise to post-cruise).

Within the post-cruise-only sub-sample ($n=96$) the mean age of caregivers completing the survey was $M=46.90$ years old ($SD= 8.61$). Table 2 contains all study demographic. Caregivers

reported a mean of $M=2.00$ children ($SD= .86$), and $M=1.11$ children with special needs ($SD= .375$). With regards to ethnicity, 88.50% of caregiver reports were White, 4.20% Hispanic, Latino or of Spanish origin, 4.20% Black, and 1.00% Asian. The largest proportion of caregivers were located in the United States with 43.80% from the Northeast, 17.70% the Southeast, 1.00% the Northwest, 10.40% the Southwest, and 21.90% the Midwest. Only 3.10% were from outside of the U.S. With regard to marital status, 78.10% of caregivers reported being currently married/committed partnership, 3.10% widowed, 12.50% divorced, 1.00% separated, and 4.20% never married/partnered. Incomes ranged from 9.00% having an income of less than \$20,000, 4.20% an income ranging from \$20,000-\$34,000, 5.20% an income ranging from \$35,000-\$49,000, 12.50% an income ranging from \$50,000-\$74,000, 16.70% an income ranging from \$75,000-\$99,000, 27.10% an income ranging from \$100,000-\$149,000, 9.40% an income ranging from \$150,000-\$199,000, and 11.50% an income of \$200,000 or more. When asked about the caregiver's relationship to the individual with special needs, 70.00% of caregivers identified that the individual was their son, 13.00% their daughter, 5.00% their grandson and 7.00% of caregivers identified that the relationship was something other. Caregivers also reported on the ages of their child with special needs. The average age was $M = 12.59$ ($SD = 1.32$), and children's ages ranged from 4 to 28 years old.

Table 1
Study 1 Demographic Characteristics for Participating Caregivers Post Cruise Sub-sample (n=96)

<i>Characteristics</i>	<i>N</i>	<i>%</i>
Age		
25-29	2	2.40
30-34	3	3.60
35-39	12	14.20
40-44	15	21.50
45-49	21	25.00
50-54	11	13.10

Table 1 cont'd	7	8.30
55-59	8	9.50
60-64	2	2.40
65-69		
Ethnicity		
White	85	90.40
Hispanic/Latino/ Spanish	4	4.30
Origin	4	4.30
Black	1	1.10
Asian or Pacific Islander		
Location		
Northeast US	42	44.70
Southeast US	17	18.10
Northwest US	1	1.10
Southwest US	10	10.60
Central US	21	22.30
Outside USA	3	3.20
Income		
Less than \$20,000	9	9.80
\$20,000 to \$34,000	4	4.30
\$35,000 to \$49,000	5	5.40
\$50,000 to \$74,000	12	13.00
\$75,000 to \$99,000	16	17.40
\$100,000 to \$149,000	26	28.30
\$150,000 to \$199,000	9	9.80
\$200,000 or more	11	12.00

Table 2

Study 1 Child Characteristics

Characteristics	<i>N</i>	%
Number of Children	-	
0	1	1.10
1	27	29.00
2	40	43.00
3	21	22.60
4	4	4.30

Children with Special Needs

Table 2 cont'd		83	89.20
	1	9	9.70
	2	1	1.10
	3		
Relationship			
	Son	70	72.90
	Daughter	13	13.50
	Grandson	5	5.30
	Other	7	7.30

Within the pre-and-post sub-sample ($n=16$) the mean age of caregivers completing the survey was $M= 48.90$ years old ($SD= 10.10$). Caregivers reported a total of $M= 2.13$ children ($SD= .52$), with $M= 1.33$ children with special needs ($SD= .49$). With regards to ethnicity, 81.30% of caregivers identified as White, 6.30% Hispanic, Latino or Spanish origin, or American Native, 6.30% Black, and 6.30% Asian. In terms of geographical location, 37.50% of caregivers were located in Northeast United States, 18.80% Southeast United States, 0% Northwest United States, 6.30% Southwest United States, and 37.50% Central United States. With regard to marital status, 75.00% of caregivers reported being currently married/ committed partnership, 18.80% divorced, and 6.30% never married/partnered. Incomes ranged with 12.50% having an income of less than \$20,000, 12.50% an income ranging from \$20,000-\$34,000, 12.50% an income ranging from \$35,000-\$49,000, 25% an income ranging from \$50,000-\$74,000, 12.500% an income ranging from \$75,000-\$99,000, and 25.00% an income ranging from \$100,000-\$149,000. When asked about the caregiver's relationship to the individual with special needs, 75.00% of caregivers identified that the individual was their son, 6.30% their daughter, 6.30% their grandson and 12.50% of caregivers identified that the relationship was

something other. Caregivers also reported on the ages of the child with special needs. Ages ranged from 8 to 28 years old ($M= 16.20$, $SD= 6.37$).

Table 3

Study 1 Demographic Characteristics for Participating Caregivers Pre and Post Cruise Sub-sample (n=16)

Characteristics	N	%
Age	-	
30-34	1	7.70
35-39	1	7.70
40-44	4	30.80
50-54	3	23.10
60-64	3	23.10
65-69	1	7.70
Ethnicity		
White	13	81.30
Hispanic/Latino/ Spanish Origin	1	6.30
Native	1	6.30
Black		
Asian or Pacific Islander		
Location		
Northeast US	6	37.50
Southeast US	3	18.80
Southwest US	1	6.30
Central US	6	37.50
Income		
Less than \$20,000	2	12.50
\$20,000 to \$34,000	2	12.50
\$35,000 to \$49,000	2	12.50
\$50,000 to \$74,000	4	25.00
\$75,000 to \$99,000	2	12.50
\$100,000 to \$149,000	4	25.00

Table 4

Continued Study 1 Demographic Characteristics for Participating Caregivers Post Cruise Sub-sample (n=16)

Characteristics	<i>N</i>	%
Number of Children	-	
1	1	6.70
2	11	73.30
3	3	20.00

Procedure: Study 1

Participants who had cruised Autism on the Seas within the past 3 years were eligible to participant within the study one time regardless of how many times they may have cruised. A survey, generated through Qualtrics, was used to incorporate multiple measures. Caregiver identities and responses were anonymous. The surveys were distributed via email by Autism on the Seas office administration. The pre-cruise survey was distributed to all participants who were about to cruise and then the post measure was distributed three months after their sailing date. One caregiver per child who cruised was eligible to participate in the study, and if the caregiver cruised with multiple children with special needs, they were asked to complete the measure with the eldest child in mind. There was an incentive raffle for participants consisting of a 25% off discount on their next cruise booked. Drawings were to be held every six months.

Intervention. Autism on the Seas offers a variety of accommodations to every family cruising with professional staff. Six to nine weeks prior to the cruise, caregivers are required to fill out a questionnaire indicating the needs, and preferences of their child. Upon boarding,

families are greeted by staff in the port, and guided through priority embarkation. They are then provided with reserved seating (for every meal) and a private muster drill with staff. At the beginning of the cruise, parents are encouraged to schedule introductory sessions with staff. During this time, parents can discuss the questionnaire and more specific preferences and concerns with the staff. Throughout the cruise, all families have access to a variety of private staffed activities depending on the ship's features. During these non-drop-off activities, families and siblings are encouraged to participate with staff, but are not required. These activities include rock wall, ice-skating, "jump zone," inline skating, zip line, pool slide, bumper cars, basketball court, flow-rider, ropes course, etc. Respite takes place for at least 2 hours each evening after dinner. Respite is the only time during the cruise when caregivers can drop off their child with special needs and any siblings. On sea days, respite occurs in 2 sessions of 2 hours each. During respite children are provided with many sensory friendly toys and games. Older children are given the option to explore the ship with staff, and attend ship activities such as karaoke or a show. All shows have reserved seating for families. Staff dine with all families for all meals. Excursions are provided at 2 ports. During excursions families have the option of travelling with staff to a predetermined destination such as a beach or trolley tour depending on the cruise. The Autism on the Seas organization promotes a family vacation, where families are encouraged to enjoy activities together but also provides caregivers with the opportunities to refresh by providing daily respite services.

Autism on the Seas staff are all carefully screened with national background checks and required to complete a phone interview before receiving any cruise contracts. Staff must be at least 21 years old, hold a 4-year degree in a qualifying major relating to behavior therapy, child development or special education, and have at least 1-year experience with individuals with

developmental disabilities. Staff have extensive experience caring for individuals of all ages with special needs and can manage any level of behaviors. Staff are led by Group leaders and complete a training prior to boarding the ship. Staff are in constant contact with and under the supervision of the group leader. They attend ongoing staff meetings throughout the duration of the cruise. Staff members are given ongoing feedback and are formally evaluated at the end of every cruise.

Measures: Study 1

Caregiver Stress. The caregiver stress level was captured through The Parenting Stress Index-Short Form (PSI/SFPSI/SF; Abidin 1990). The PSI is a self-report measure that assesses parenting stress in parents of children ages 3 months-10 years. It is comprised of 36 items pertaining to different situations and parental emotions. Caregivers were asked to indicate their level of agreement with each item on a Likert Scale from 1 (strongly agree) to 5 (strongly disagree). The measure is broken down into three sub-scales, *Parental Distress*, *Parent-Child Dysfunction Interaction* and *Difficult Child Characteristics*. The *Parental Distress* sub-scale assesses how parents feel in a parenting role, for example, “Since having a child I feel that I am almost never able to do things I like to do.” The *Parent-Child Dysfunction Interaction* sub-scale assess the interactional system between the parent and child, for example, “Most times I feel that my child does not like me and does not want to be close to me.” The *Difficult Child* sub-scale assesses parent perceptions about their child, for example, “My child seems to cry or fuss more often than most children.” The PSI/SF has been shown to have high internal consistency and test-retest reliability. The measure has been used widely among parents of children with special needs. In the present study, the raw scores (i.e sum scores) were created and used in subsequent analyses. Cronbach's alpha was calculated to assess the reliability of this measure in the present

study using data from Study 1 sub-sample 1. Alphas were as follows: Total Stress ($\alpha = .91$), Parental Distress ($\alpha = .88$), Parent-Child Dysfunction ($\alpha = .80$), and Difficult Child Characteristics ($\alpha = .84$). Concurrent validity was established by the authors of this measure with the full PSI version, calculating correlations ranging from 0.73 to 0.95 with gross scores for this instrument's three subscales as well as the total scale (Abidin, 1995).

Family Quality of Life. Caregivers' reports of the family quality of life was captured through the Beach Center Family Quality of Life Survey (Beach Center on Disabilities, 2006). The Beach Center Family Quality of Life survey is a self-report measure that assesses five subscales including family interaction, parenting, emotional well-being, physical/ material well-being, and disability-related support. The final version of the measure was narrowed down by the authors to 25 items, and all 25 items were used in this research. Participants were asked to rate their level of satisfaction on a Likert scale ranging from 1 (very dissatisfied) to 5 (very satisfied) for each item. The *family interaction* subscale assessed the family's emotions with regards to spending time together, for example, "My family enjoys spending time together." The *parenting* subscale assessed family caregivers' willingness to help their child with special needs, for example, "Family members help the children learn to be independent." The *emotion well-being* subscale assessed the family's support system, for example, "My family has the support we need to relieve stress." The subscale on *physical/material well being* assessed the family's resources, for example, "My family members have transportation to get to the places they need to be." The final subscale, *disability-related support* assessed the support provided for the family member with special needs, for example, "My family member with special needs has support to make progress in the workplace." The Beach Center Family Quality of Life Scale has been widely used for its intended population, families with special needs. The authors report strong test-retest

reliability and high convergent validity (Beach Center on Disabilities, 2006). Test-retest reliability was examined in both importance and satisfaction responses for each of the FQOL subscales. Because there were no hypotheses on the subscales for the present study, the total measure (overall quality of life) was used. In the present study, caregivers' reports of overall quality of life (total measure) was examined. Cronbach's alpha was $\alpha = .92$ in the present study.

Caregiver Social Network. The caregivers' reports of their social network were captured through the Berkman-Syme Network Index (SNI). The SNI is a self-report measure that assesses 12 types of social relationships. These include relationships with a spouse, parents, children. Other family members, close neighbors, friends, coworkers, schoolmates, and members of groups with and without religious affiliation. Participants were asked to report the number of relationships they have with regards to each item. For example: "How many close friends do you have? Close friends are people that you feel at ease with/ can talk to about private matters." The authors of the SNI report high reliability, Cronbach's alpha was .84. Cronbach's alpha was calculated to assess the reliability of this measure in the present study ($\alpha = .67$). This lower alpha may reflect the fact that the caregivers may or may not report *each* of the types of relationships reflected in the measure, thus lowering social network raw scores (i.e., coworker; religious affiliation).

Caregiver Self-efficacy. The caregiver self-efficacy was captured through Self-Efficacy for Parenting Tasks Index (SEPTI) (SEPTI; Coleman & Karraker, 2000). The SEPTI is a self-report measure that assesses self-efficacy in parents of elementary school-aged children. Caregivers were asked to rank their level of agreement with each item on a Likert Scale from 1 (strongly agree) to 6 (strongly disagree). For example: "The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have

acquired.” In this study, researchers used 17 out of the 36 items pertaining to domain-specific self-efficacy. Only the items pertaining to parenting were utilized, the items relating to coping were eliminated. The SEPTI has been shown to have high reliability. Construct validity was investigated by the authors of the measure through the use of principle components factor analysis with oblique rotation. A forced five-factor solution, accounting for a total of 51.9% variance provided some support for the five categories present in the measure. Cronbach's alpha coefficient for the full scale was found to equal .91 (Coleman & Karraker, 2000). Cronbach's alpha was calculated to assess the reliability of this measure in the present study ($\alpha = .84$). It is possible that this lower reliability reflects the fact that the abbreviated measure was used.

Respite Utilization. The caregiver’s respite utilization was measured through a self-report survey that required caregivers to check each of the activities in which their child participated in during the respite vacation. The measure indicated participation or non-participation within a series of activities. The total respite utilization variable was created to reflect the total number of activities in which participants engaged. The complete list of activities assisted by Autism on the Seas staff was provided by the Autism on the Seas organization.

Self-Care Assessment. The caregivers’ activities and the amount of time they took away from their kids was measured through a self-report survey. This survey required caregivers to check the frequency of times caregivers took time away from their child and caring for their own personal health. This variable was calculated as respite separate from the intervention.

Severity. Caregivers reported their preception of the severity of their child’s ASD on two separate scales: social communication deficits and restricted interests and repetitive behaviors. Both scales utilized Likert Scales ranging from 0-3. Social communication deficits

scores of 0 indicated none, scores of 1 indicated mild support needs (i.e., “Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions”), scores of 2 indicated substantial support needs (i.e., “Marked deficits in verbal and nonverbal social communication skills; social communication skills apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others”), and scores of 3 indicated severe/requiring very substantial support (i.e., “Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.”)

Restricted interests and repetitive behaviors scores of 0 indicated none, scores of 1 indicated mild support needs (i.e., “Rituals and repetitive behaviors (RRBs) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRBs or to be redirected from fixated interest”), scores of 2 indicated substantial support needs (i.e. “RRBs and/or preoccupations and/or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRBs are interrupted; difficult to redirect from fixated interests”), and scores of 3 indicated severe requiring very substantial support (i.e., “Preoccupations, fixed rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.”)

These scores were averaged to calculate child severity. Scores of pre and post child severity were averaged when caregivers reported differences in these scores across the two reporting time points.

Analytic Plan: Study 1

Study 1 aimed to investigate individual differences in dimensions of psychosocial well-being among parents of children with ASD, and the effect of participating in a respite vacation program provided to families with respect to severity of ASD and social communication disorders on parents' psychosocial well-being. The first research question asked whether there is an association between caregiver stress, caregiver social network, family quality of life, and caregiver self-efficacy. Spearman's correlations analyses were utilized. It was hypothesized that caregiver stress (i.e., a negative index of well-being) would be correlated negatively with the remaining variables, while the other variables (i.e., positive indices of well-being) would correlate positively.

The second research question addressed the potential impact of child severity on the association between respite and family well-being. These research questions were tested with regression models such that family well-being was the dependent variable, and the independent variables was respite utilization, child severity, and the interaction between respite and child severity (respite*severity).

The remaining quantitative research questions addressed whether there was a difference in caregivers' reports of well-being (i.e., stress, social network, family quality of life, and caregivers' self-efficacy) after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver stress prior to the vacation when controlling for child characteristics. Repeated measures ANOVA analyses were utilized between pre-cruise and post-cruise data for participants who have answered both surveys. For any significant differences, severity of ASD with regards to social communication and repetitive and restricted behaviors was controlled to determine whether the differences held after including this covariate. The four analyses were

run and analyzed separately. It was hypothesized that the Autism on the Seas respite vacation experience will positively affect caregivers. In other words, post-cruise data will reflect decreased caregiver report of stress, increased caregiver report of social network, increased caregiver report of family quality of life, and increased caregiver report of self-efficacy. Finally, given the small sample size, non-parametric analyses were conducted to follow-up any non-significant repeated measures ANOVAs.

Qualitative Research Design: Study 2

The qualitative study aimed to draw a general picture of individual changes that occurred over time as a function of respite using a case study approach. The methodological approach to this study was based on “description, interpretation” and “identification of recurrent patterns in the form of themes” (Merriam, 1998, p. 12). The case being studied was of many individuals in the context of one particular respite program. Several sources of data were utilized for purposes of triangulation—interviews, demographic survey, pre and post cruise surveys, and child questionnaires. These data sources, described in detail below, were used to capture practices and attitudes of the participants through their own lens and through the observations of the researcher.

The researcher. The researcher was a special education teacher, with 16 years of previous experiences with working with families and individuals with ASD and is a doctoral candidate in Autism and Intellectual Disabilities at Teachers College, Columbia University. The researcher was the group leader with whom all the participants except one couple cruised with. Group leaders are in charge of all accommodations with the cruise line and are the person whom the parents report to with any problems. The group leader is also responsible for all staff training and assignments. The researcher got to know the participants very well, as she saw them for

nine days straight, and many hours throughout each day. They ate three meals together on all nine days, and the researcher was in charge of every activity they attended. However, this also could result in researcher bias. Although the researcher intended to ask participants about respite in its entirety and all forms of respite, they had experienced, parents only evaluated the program using the Autism on the Seas evaluations forms. According to Autism on the Seas the evaluations were very positive. The researcher asked the participants to report on other forms of respite as a neutral researcher and not as an Autism on the Seas volunteer in the company. The researcher developed a close relationship with my participants and got to know their child and their family; they seemed comfortable with her throughout the interview and really opened up.

Participants: Study 2

All interviews took place on the phone. Participants were recruited by social media. The researcher posted a message on a social media site requesting caregivers to assist in a research project with regards to the topic of respite. This post was accessible by families who had most recently cruised with the researcher in August of 2017 through a program called Autism on the Seas. Autism on the Seas is an organization that provides services to accommodate families with children with ASD and other special needs during a vacation. The organization granted permission to recruit participants and utilize staff notes. The majority of participating caregivers cruised most recently in August of 2017 and engaged in phone interviews with the researcher, with whom they were all familiar. There was the exception of one family who did not cruise with the researcher but instead met and spent significant time with the researcher at a fundraiser.

All participants completed an informed consent form prior to the start of the study. All participants were given pseudonyms when described in the study. Participants were allowed to leave the study or stop the interview at any time, all participants completed the study.

Participant 1: Joe. Joe is a 47-year-old male from the Northeastern United States. He is white and has completed advanced graduate work or PhD. His income is roughly \$150,000-\$199,999. I met Joe on a cruise with his six-year-old daughter and his father in August 2017. This was Joe's first cruise with Autism on the Seas. Joe is divorced, and shares custody with his mother-in-law. His daughter has a diagnosis of ASD and Attention Deficit/ Hyperactivity Disorder (ADHD). When asked to comment on his daughter's social communication, he left the categories blank, however, when asked the same categories to describe his daughter's restricted interests and repetitive behaviors, he responded "mild" (requiring minimal support). Joe's daughter stays with him over the week and visits her maternal grandmother on the weekends. She is an only child. Joe is retired and takes consulting contracts as they fit into his schedule. He is also very active in his daughter's life, observing every therapy session and taking on the role of "Class Mom" at school this year. Joe and his daughter live with Joe's mother.

Participants 2 and 3: Greg and Cara. Greg and Cara have been married for 14 years. Both are 38 years old and from the Northeastern US. Greg is white and has a master's degree. His income is over \$200,000. Cara is white and has a bachelor's degree. Her income is less than \$20,000. I met Greg and Cara on a cruise with their eight-year-old son with ASD, severe speech delay (nonverbal), Pica, and von Willebrand's disorder in August, 2017. Von Willebrand's disease is a genetic disorder caused by missing or defective von Willebrand factor, which is a clotting protein. Individuals with Von Willebrand's disorder have symptoms related to recurrent or prolonged bleeding. When asked to comment on their son's social communication, Greg checked "severe" (requiring very substantial support), while Cara checked "moderate" (requiring substantial support). When asked the same categories to describe their son's restricted interests and repetitive behaviors, Greg selected "moderate" (requiring substantial support), while Cara

checked moderate (requiring substantial support). This was Greg's second cruise with Autism on the Seas, while this was Cara's third cruise within the past year with Autism on the Seas. Greg is employed full time. Although he is able to work from home a lot, he also travels for business a lot. Cara is a stay at home mom, who occasionally works on contracts.

Participants 4 & 5: Mark and Ruby. Mark and Ruby have been married for 21 years. Mark is 53 years old and Ruby is 51 years old. Both are white and from the Northeastern US. Mark has completed a master's degree and has an income between \$150,000-\$199,000. Ruby has completed her PhD and has an income over \$200,000. I met Mark and Ruby on a cruise with their 18-year-old son, diagnosed with ASD and Down syndrome, and 16-year-old daughter in August 2015 and have cruised with them twice. When asked to comment on their son's social communication, both Mark and Ruby checked "severe" (requiring very substantial support). When asked the same categories to describe their son's restricted interests and repetitive behaviors, both Mark and Ruby stated that their son needed "moderate" support (requiring substantial support). This was the family's third cruise over the past three years with Autism on the Seas. The couple takes turns travelling for work.

Participants 6 & 7: Ray and Jill. Ray and Jill have been married for 12 years. Both are white and from the Northeastern US. Both are 42 years old. Ray has a bachelor's degree and is currently retired. Jill has a master's degree and has an income between \$75,000-\$99,000. I met Ray and Jill on a cruise with their 8-year-old son, diagnosed with ASD, and 4-year-old daughter in August 2017. When asked to comment on their son's social communication, Ray checked "mild" (requiring support), while Jill checked "moderate" (requiring substantial support). When asked the same categories to describe their son behaviorally, Ray checked "mild" (requiring

support), while Jill checked “moderate” (requiring substantial support). Ray is a stay at home dad, while Jill works fulltime.

Participants 8 & 9: Mercy and Peter. Mercy and Peter have been married for 11 years. Mercy is 49 years old, and Peter is 48 years old. Both are white and from the Northeastern US. Mercy has a bachelor’s degree and has an income between \$75,000-\$99,000. Peter has a master’s degree and has an income between \$75,000-\$99,000. I met Mercy and Peter with their 8-year-old son, diagnosed with ASD and apraxia, in August 2017 on a cruise. When asked to comment on their son’s social communication, both Mercy and Peter checked “severe” (requiring substantial support). When asked the same categories to describe their son behaviorally, both parents checked “mild” (requiring support). Mercy and Peter are both employed.

Participants 10 & 11: Jordan and Roger. Jordan and Roger have been married for 20 years. Jordan is 49 years old and Roger is 51 years old. Both are asian and from the Northeastern US. Jordan has completed some college but is not employed. Roger has a bachelor’s degree and has an income between over \$200,000. I met Roger with his 16-year-old son, diagnosed with ASD PDD-NOS at a fundraiser in September 2018. When asked to comment on their son’s social communication, Jordan checked “mild” (requiring support) while Roger checked “moderate” (requiring substantial support). When asked the same categories to describe their son behaviorally, Jordan checked “moderate” (requiring substantial support) while Roger checked “severe” (requiring very substantial support).

Participants 12 & 13: Noa and Karl have been married for 22 years. Noa is 47 years old and Karl is 48 years old. Both are black and from the Northeastern US. Noa has completed advanced graduate work or PhD and has an income over \$200,000. Karl has also completed

advanced graduate work or PhD but did not report his income. I met Noa and Karl on a cruise with their 19-year-old daughter, diagnosed with ASD and Down syndrome, and 16-year-old daughter in August 2017 on a cruise. When asked to comment on their daughter's social communication, Noa checked “moderate” (requiring substantial support) while Karl checked “severe” (requiring very substantial support). When asked the same categories to describe their daughter’s restricted interests and repetitive behaviors, both Noa and Karl responded “moderate” (requiring substantial support).

Table 5
Study 2 Demographic Characteristics for Participating Caregivers

Participant Pseudo	Age	Ethnicity	Location	Marital Status	Income	Education Completed
Joe	47	White	Northeast US	Divorced	\$150,000 to \$199,000	Advanced graduate work or PhD
Greg	38	White	Northeast US	14 years	\$200,000 or more	Master’s Degree
Cara	38	White	Northeast US	14 years	Less than \$20,000	Bachelor’s Degree
Mark	53	White	Northeast US	21 years	\$150,000 to \$199,000	Master’s Degree
Ruby	51	White	Northeast US	21 years	\$200,000 or more	Advanced graduate work or PhD
Ray	42	White	Northeast US	12 years	Currently Unemployed	Bachelor’s Degree

Table 5 cont'd

Jill	42	White	Northeast US	12 years	\$75,000 to \$99,000	Master's Degree
Mercy	49	White	Northeast US	11 years	\$75,000 to \$99,000	Bachelor's Degree
Peter	48	White	Northeast US	11 years	\$75,000 to \$99,000	Master's Degree
Jordan	48	Asian or Pacific Islander	Northeast US	20 years	Currently Unemployed	Some college
Roger	51	Asian or Pacific Islander	Northeast US	20 years	\$200,000 or more	Bachelor's Degree
Noa	47	Black	Northeast US	22 years	\$200,000 or more	Advanced graduate work or PhD
Karl	48	Black	Northeast US	22 years	Not Reported	Advanced graduate work or PhD

Table 6

Continued: Study 2 Demographic Characteristics for Participating Caregivers

Participant Pseudo	Relationship with Child	Child Age	Child Diagnosis	Number of Children	Children with Special Needs
Joe	Father	6	ASD/ ADHD	1	1
Greg	Father	8	ASD/ Nonverbal/ Pica Von Willebrand's Disorder	1	1
Cara	Mother	8	ASD/ Nonverbal/ Pica Von Willebrand's Disorder	1	1
Mark	Father	18	ASD Down Syndrome	2	1
Ruby	Mother	18	ASD Down Syndrome	2	1
Ray	Father	8	ASD/ PDD- NOS	2	1

Table 6 cont'd

Jill	Mother	8	ASD/ PDD- NOS	2	1
Mercy	Mother	8	ASD/ Apraxia	1	1
Peter	Father	8	ASD/ Apraxia	1	1
Jordan	Mother	16	ASD/ PDD- NOS	2	1
Roger	Father	16	ASD/ PDD- NOS	2	1
Noa	Mother	19	ASD	1	1
Karl	Father	19	ASD	1	1

Measures: Study 2

Demographic Survey. A demographic survey was distributed to participants prior to conducting the interview. Participants spent approximately ten minutes filling out this survey on their own time. Participants were asked to fill out information such as levels of age, ethnicity, location, marital status, income, highest level of education completed, number of children,

number of children with special needs, number of adults and number of children living in household, relationship with individual with special needs, age of child, formal diagnosis of child, behavior classification and communication classification. This was a different survey from Study 1. The portion of this survey that was accessed through this qualitative study focused on the diagnosis, behavior classification and communication classification as reported by each caregiver. Classification for both behavior and communication as well as diagnosis responses were compared amongst the caregivers to detect any differences between mother and father caregivers. The demographic survey also allowed for easier scheduling of the interview. A copy of the demographics survey can be found in Appendix B.

Interviews. Semi-structured interviews were conducted via the phone. Interviews lasted for approximately one hour. Husbands and wives were interviewed separately. Participants were posed a series of questions about their experiences with respite. Follow up questions were then posed. All interviews were audio-recorded with an app on the iPad or Garage Band on the MacBook and then transcribed by the researcher. The interview protocol can be found in Appendix B.

Pre-Cruise Questionnaire. The pre-cruise questionnaire is a survey distributed by Autism on the Seas prior to cruising. The questionnaire is open-ended and gives caregivers an opportunity to write down the specific needs, behaviors, and interests of their child.

Post-Cruise Staff Notes. The post-cruise staff notes allow staff to evaluate the child with special needs in two categories. The first category asks staff to state how often the child requires individualized attention. The second category asks staff to state the amount of aggression the child exhibits. Staff also add notes to inform any future staff members about the child's behaviors, interests, or needs.

Analytic Plan: Study 2

Study 2 aims to identify the barriers and components of respite that are most beneficial to caregivers, perceptions of respite, and the varying perspectives of husbands and wives. The study addresses how respite is related to the well-being of caregivers of children with ASD, what are the key components and barriers of respite, how do perceptions of respite vary between husbands and wives, and what the benefits of respite are for individuals with ASD as perceived by their caregiver(s). These research questions were all analyzed through open coding and then axial coding to find data trends and themes. The researcher was curious to know in what ways respite would bring positive experiences to caregivers, allowing caregivers to take time to maintain their own well-being psychologically and physically.

Chapter IV

Results

Planned Analyses

The Autism on the Seas respite vacation experience was measured as an intervention model for respite. The researcher conducted parametric repeated measures ANOVAs to assess differences in parents' reports of well-being before and after the Autism on the Seas experience. When significant differences were identified, ANCOVAs were then conducted to determine if differences remained after controlling for meaningful covariate (parent reported severity). Given the small sample size, the researcher also conducted non-parametric analysis to grasp a better understanding of the pattern change between pre and post Autism on the Seas respite experience.

Study 1 Preliminary Analysis

Descriptive Analysis. Descriptive analyses were conducted on caregiver reports of well-being. For the measure of caregiver stress, caregivers reported on a Likert Scale of 1 to 5; responses were reverse coded, with higher scores indicating more stress. In the post-only sub-sample ($N=96$), caregivers reported a $M=104.02$, ($SD= 19.69$) indicating they were in the 86th percentile, slightly above the normal range of stress relative to the measure's normative sample (Abidin, 1995). In the pre and post sub-sample ($N=16$), caregivers reported $M= 99.13$ ($SD= 29.43$) at pre test, indicating they were in the 76th percentile, in the normal range of stress relative to the measure's normative sample pre cruise. Post cruise caregivers reported $M=103.86$ ($SD= 22.30$), indicating they were in the 86th percentile, slightly elevated stress relative to the measure's normative sample. Thus, caregivers within both sub-samples reported higher stress than the typical population.

When asked about social network, caregivers reported on a scale indicating how many individuals they felt they could depend on or how many events they attended. These values were coded such that None =0, 1 or 2= 1, 3-5=2, 6-9= 3, 10 or more= 4. For questions that asked about frequency in participation Never or almost never =0, Once or twice a year =1, Every few months =2, Once or twice a month=3, More than once a week =4. All items ranged from 0 to 4 and were averaged to create a composite social network variable such that higher scores reflected a larger social network. Caregivers reported an average of $M= 1.93$ ($SD=.49$) in the post only sub-sample. In the pre and post sub-sample, caregivers reported $M= 1.79$ ($SD=.40$) on the pre cruise survey, and $M=1.86$ ($SD=.46$) on the post cruise survey. Thus, on average, caregivers reported that they had social networks that included between two to five individuals and attendance at events between once per year to every few months.

With regards to the measure of family quality of life, caregivers reported on a Likert Scale such that Very dissatisfied= 1, Dissatisfied =2, Neither =3, Satisfied =4, and Very Satisfied =5. Thus, higher scores reflected a higher overall family quality of life. Caregivers reported $M=3.69$ ($SD= .58$) in the post only sample. In the pre and post sub-sample, caregivers reported $M=3.40$, $SD=.63$ pre cruise survey, and $M=3.72$, $SD=.44$ post cruise survey. Thus, on average, caregivers reported that family quality of life was less than “satisfied.”

For the measure of caregiver self-efficacy, caregivers reported on a Likert Scale such that with higher scores indicating higher self-efficacy. In the post only survey sample, caregivers reported $M=3.06$, $SD= .66$. In the pre and post sub-sample, caregivers reported $M=2.99$, $SD=.73$ pre cruise survey, and $M=3.04$, $SD= .73$ post cruise survey. Thus, caregivers reported that self-efficacy was less than the general parenting population.

Caregivers also completed questions relating to self-care, thus accounting for respite. Caregivers reported on a Likert Scale such that Never=1, Less than monthly=2, Monthly=3, Weekly= 4, and Daily or almost daily=5. Caregivers reported $M=2.80$, $SD= 1.11$ in the post only sub-sample. In the pre and post sub-sample, caregivers reported $M= 2.61$, $SD= 1.33$ pre cruise survey. Thus, caregivers reported that they were given time to themselves “less than monthly.”

When asked about the number of activities the child with special needs attended outside the house, caregivers reported on a Likert Scale with higher scores indicating higher frequency of activity. Caregivers reported $M=2.39$, $SD= .44$ in the post-cruise survey sample. In the pre and post sub-sample ($n=16$), caregivers reported $M=2.52$, $SD=.58$. Thus, caregivers reported that their children “seldom” to “occasionally” attended activities outside the house.

Child severity was reported by caregivers on a scale measuring from no communication impairments and repetitive behaviors (1), minimal communication impairments/ repetitive behaviors (2), moderate communication impairments/repetitive behaviors (3), and severe communication impairments/ repetitive behaviors (4). Caregivers reported an overall mean for both communication impairments and repetitive behaviors $M= 2.64$, $SD= .69$ with regards to the severity of their child in the post-cruise survey sample. In the pre and post only sub-sample, caregivers reported $M=2.61$, $SD=1.33$. Thus, children in both sub-samples were between moderate to severe in their combined communication and repetitive behavior impairments.

Correlations Among Parent Well-being, Child Characteristics, and Demographics.

Bivariate correlations between parent well-being and both demographic and child characteristic variables were conducted. Spearman’s correlational analyses were conducted to determine bivariate relations between caregiver reports of respite, child’s activities out of the house, and

number of activities in which the caregiver participated during the cruise. Correlations between caregiver composite variables revealed that respite at home was positively correlated with income, $r_s = .37, p < .001$. Finally, the number of recreational activities that the child participated in out of the house was found to be negatively correlated to stress, $r_s(40) = -.25, p = .047$.

Study 1 Test of Research Questions

Research Question 1. Is there relation between caregiver stress, caregiver social network, family quality of life, and caregiver self-efficacy? This first research question examined the relation between each of the caregiver well-being variables. All questionnaires were self-reported by the caregiver.

Spearman's correlation analyses were utilized amongst the post only sub-sample ($n=96$). Results from this analysis concluded that self-efficacy was positively correlated with social networking, $r_s(40) = .309, p = .004$, and negatively correlated with stress $r_s(40) = -.555, p < .001$ and positively with quality of life, $r_s(40) = .491, p < .001$. Social network was positively correlated with quality of life, $r_s(40) = .258, p = .016$, and negatively correlated with stress $r_s = -.313, p = .003$, and self-efficacy, $r_s = -.309, p = .004$. Quality of life was correlated negatively with stress, $r_s(40) = -.508, p < .001$. and positively with social network, $r_s = .258, p = .016$.

Refer to Table 7.

Table 7
Spearman's Correlation for Caregiver Well-Being Variables and Child Characteristics

Measures	1	2	3	4	5	6	7	8
1. Stress	-							
2. QoL	-.508**	-						
3. SN	-.313**	.258*	-					
4. SE	-.555***	.491**	.309**	-				
5. Severity	.140	-.086	-.180	.223*	-			
6. Respite	-2.40*	.154	.261*	.051	-.012	-		
7. Rec	-.243*	.190	.230*	-.249*	-.021	.149	-	
8. Cruise	.127	-.011	-.167	.209	.006	.057	-.045	-

Note: QoL= Quality of Life, SN= Social Network, SE= Self Efficacy, Rec= Recreational Activities, Cruise= Cruise Activities Onboard

** Correlation is significant at the 0.01 level (2tailed)

*Correlation is significant at the 0.05 level (2 tailed)

Research Question 2. Was there a stronger association between respite and family outcomes for families of children with more severe disabilities? The second research question addressed the potential impact of child severity on the association between respite and family well-being. These research questions were tested with regression such that family well-being was the dependent variable, and the independent variables entered into the model were respite utilization at home, parent-rated ASD symptoms severity, and the interaction between home respite and symptom severity (respite*severity). Refer to Table 8. There were no significant differences among the associations found to be a function of severity.

2a. Was there a stronger association between respite use and parenting stress for families of children with more severe disabilities? Although the results of the regression indicated a significant overall model $F(3, 86)=2.917, p=.039$, there was not a significant

interaction between respite and stress for families of children with more severe disabilities, $t(86) = -1.12, p = .265$. Refer to Table 8.

2b. Was there a stronger association between respite use and family QoL for families of children with more severe disabilities? The results of the regression indicated a nonsignificant overall model in predicting QoL with respite, severity, and respite*severity, $F(3, 82) = 1.403, p = .248$. Refer to Table 8.

2c. Was there a stronger association between respite and social network for families of children with more severe disabilities? The results of the regression indicated a nonsignificant overall model in predicting social network with respite, severity, and respite*severity, $F(3, 85) = 2.527, p = .063$. Refer to Table 8.

2d. Was there a stronger association between respite and self-efficacy for families of children with more severe disabilities? The results of the regression indicated a nonsignificant overall model in predicting self-efficacy with respite, severity, and respite*severity, $F(3, 81) = 1.339, p = .267$. Refer to Table 8.

Table 8

*Regression Table to Test Interaction Between Respite * Severity on Caregiver Well-Being Variables*

	B	Std. Error	Standardized Coefficients Beta	<i>t</i>	<i>p</i>
Dependent Variable: Stress					
Model $F(3, 89) = 2.917, p = .039$					
Respite utilization at home	4.94	8.71	.28	.57	.57
ASD symptom Severity	13.45	9.82	.46	1.37	.17

Severity * Respite	-3.58	3.19	-.64	-1.12	.27
Dependent Variable: QoL					
Model $F(3, 85) = 1.403, p = .248$					
Respite	.231	.269	.445	.860	.392
Severity	.079	.305	.096	.261	.795
Severity * Respite	-.048	.098	-.300	-.495	.622
Table 8 cont'd					
Dependent Variable: Social Network					
Model $F(3, 88) = 2.527, p = .063$					
Respite	-.015	.191	-.039	-.079	.937
Severity	-.197	.215	-.314	-.917	.362
Severity * Respite	.041	.070	.340	.594	.554
Dependent Variable: Self-Efficacy					
Model $F(3, 88) = 2.581, p = .059$					
Respite	.016	.217	.036	.073	.942
Severity	-.184	.244	-.257	-.753	.454
Severity * Respite	.037	.079	.266	.466	.643

Research Question 3. Was there a difference in caregivers' reports of well-being three months after their sailing on the Autism on the Seas respite vacation when controlling for child severity? The final quantitative research question addressed whether there was a difference in caregivers' reports of well-being (i.e., stress, social network, family quality of life, and caregivers' self-efficacy) after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver stress prior to the vacation when controlling for child characteristics. For this analysis, the subset of participants with pre and post data ($n = 16$) were

included in the analysis. Repeated measures ANOVA analyses were first conducted utilizing pre-cruise and post-cruise data for participants who had completed both surveys. Four analyses were conducted to examine each of the dependent variables (i.e., indices of well-being) separately. For any analysis found to be significant, we next controlled for the severity of ASD with regards to social communication and repetitive and restricted behaviors was included as a covariate using ANCOVA. Given the small sample size, in the case of non-significant repeated measures ANOVAs, a non-parametric analysis was also conducted to examine differences. There were no significant differences found.

3a. Was there a difference in caregivers' reports of stress after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver stress prior to the vacation when controlling for child characteristics?

A repeated ANOVA was conducted to determine if there was a difference in caregivers' reported stress between pre and post cruise surveys. The results of this analysis revealed that there was not a significant difference in caregivers' reported stress after experiencing the Autism on the Seas respite vacation, $F(1, 13) = .107, p = .749$. Refer to Table 9.

A nonparametric Wilcoxon signed-ranks test was conducted to explore this difference given the small sample size. Results of this test indicated that 6 participants' stress scores decreased, indicating lower stress post cruise, however, 7 participants' stress scores increased, and 1 remained the same. A Wilcoxon signed-rank test showed that the Autism on the Seas respite vacation did not elicit a statistically significant change in stress levels ($Z = -.70, p = .944$). Refer to Table 10.

To follow-up the above-mentioned analyses, Wilcoxon signed-ranked tests were conducted on the subscales of the parenting stress measure, *Parental Distress*, *Parent-Child*

Dysfunction Interaction and Difficult Child Characteristics. For *Parental Distress*, results of the Wilcoxon signed-ranked test indicated that 8 participants' scores decreased, indicating parents felt less in a parenting role post cruise, however, 6 participants' scores increased. A Wilcoxon signed-rank test showed that the Autism on the Seas respite vacation did not elicit a statistically significant change in parent distress ($Z=-.063, p=.950$). Refer to Table 10.

For *Parent-Child Dysfunction Interaction*, results of the Wilcoxon signed-ranked test indicated all participants felt the same about the interactional system between themselves and their child post cruise. A Wilcoxon signed-rank test showed that the Autism on the Seas respite vacation did not elicit a statistically significant change in parent child dysfunction interactional system ($Z=.000, p=1.000$). Refer to Table 10.

For *Difficult Child Characteristics*, Results of the Wilcoxon signed-ranked test indicated all participants' scores remained the same, indicating parents had the same perceptions about their child post cruise. A Wilcoxon signed-rank test showed that the Autism on the Seas respite vacation did not elicit a statistically significant change in difficult child scale ($Z=.000, p=1.000$). Refer to Table 10.

3b. Was there a difference in caregivers' reports of family quality of life after experiencing the Autism on the Seas respite vacation as compared to their reports of family quality of life prior to the vacation when controlling for child characteristics?

A repeated ANOVA was conducted to determine if there was a difference in caregivers' reported family quality of life between pre and post cruise surveys. The results of this analysis revealed that there was not a significant difference in caregivers' reported family quality of life after experiencing the Autism on the Seas respite vacation, $F(1, 13)=2.356, p=.149$. Refer to Table 9.

A nonparametric Wilcoxon signed-ranks test was conducted to explore this difference given the small sample size. Results of this test indicated that 4 participants' quality of life scores decreased, indicating lower quality of life post cruise, however, 8 participants' quality of life scores increased, and 2 remained the same. A Wilcoxon signed-rank test showed that the Autism on the Seas respite vacation did not elicit a statistically significant change in stress levels ($Z=-1.374, p=.169$). Refer to Table 10.

3c. Was there a difference in caregivers' reports of their social network after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver social network prior to the vacation when controlling for child characteristics?

A repeated ANOVA was conducted to determine if there was a difference in caregivers reported social network between pre and post cruise surveys. The results of this analysis revealed that there was not a significant difference in caregivers' reported stress after experiencing the Autism on the Seas respite vacation, $F(1, 13)=.331, p=.575$. Refer to Table 9.

A nonparametric Wilcoxon signed-ranks test was conducted to explore this difference given the small sample size. Results of this test indicated that 5 participants' social network scores decreased, indicating lower social network post cruise, however, 8 participants' stress scores increased, and 1 remained the same. A Wilcoxon signed-rank test showed that the Autism on the Seas respite vacation did not elicit a statistically significant change in stress levels $Z=-.701, p=.483$). Refer to Table 10.

3d. Was there a difference in caregivers' reports of self-efficacy after experiencing the Autism on the Seas respite vacation as compared to their reports of caregiver self-efficacy prior to the vacation when controlling for child characteristics?

A repeated ANOVA was conducted to determine if there was a difference in caregivers reported self-efficacy between pre and post cruise surveys. The results of this analysis revealed that there was not a significant difference in caregivers reported self-efficacy after experiencing the Autism on the Seas respite vacation, $F(1, 12) = .100, p = .758$. Refer to Table 9.

A nonparametric Wilcoxon signed-ranks test was conducted to explore this difference given the small sample size. Results of this test indicated that 6 participants' self-efficacy scores decreased, indicating lower self-efficacy post cruise, however, 7 participants' self-efficacy scores increased, and none remained the same. A Wilcoxon signed-rank test showed that the Autism on the Seas respite vacation did not elicit a statistically significant change in stress levels ($Z = -.630, p = .529$). Refer to Table 10.

Table 9.
Repeated Measures ANOVA Source Table for Pre and Post Cruise Caregiver Well-Being Variables

	Source	Type III Sum of Squares	Df	Mean Squares	F	Sig.
Stress	Intercept	69.143	1	69.143	.107	.749
	Error	8432.857	13	648.681		
QoL	Intercept	.666	1	.666	2.356	.149
	Error	3.672	13	.282		
Social Network	Intercept	.019	1	.019	.331	.575
	Error	.733	13	.056		
Self-Efficacy	Intercept	.073	1	.073	.100	.758

Error 8.793 12 .733

Table 10.
Non-parametric Wilcoxon signed-rank Test

	Negative Ranks	Positive Ranks	Ties	N	Z	Sig.
Stress	6	7	1	14	-.70	.94
Table 10 cont'd						
Parental Distress	8	6	0	14	-.06	.95
Parent-Child Dysfunction	0	0	15	15	.00	1.00
Difficult Child Characteristics	0	0	16	16	.00	1.00
QoL	4	8	2	14	-1.37	.17
Social Network	5	8	1	14	-.70	.48
Self-Efficacy	6	7	0	13	-.52	.60

Study 2 Analysis: Emergent Themes

From an evaluation of the interview transcripts, the following three themes were revealed: (1) trusted caregivers and limited social network, (2) caregiver well-being, child well-being and severity, and (3) respite programs. Many sub-themes were evident within each. It was heartbreaking to hear caregivers talk about their limited social network and how it influences the daily routines of their lives. It was more uplifting to hear the caregivers speak about the benefits of respite on their well-being. However, I noticed that their answers varied as a function of the severity of their child’s behaviors and communications. Although the aim of the qualitative

study was to gain caregiver perspective of respite as an entirety and the daily lifestyle of caring with someone with special needs, all families brought up the Autism on the Seas respite vacation without guidance from the researcher. This commentary has been included within the results, as it was threaded into the themes.

Trusted caregiver and limited social network. When reviewing the transcripts of my interviews, I noticed that many parents commented on the lack of people with whom they would leave their child. It appears that although many of them understand the importance of time spent together as a couple, or even just time alone, they are hesitant to leave their child. These comments revealed the theme of trusted caregivers and a limited social network. Subthemes that were revealed included guilt, loneliness, being misunderstood/ identifying themselves, and cruise expansion of social network.

Guilt. Caregivers were asked how they spend time amongst themselves as a couple or even moments alone for themselves to decompress. Caregivers repeatedly reiterated across interviews that “free time was a rarity.” Many parents felt that they simply did not have anyone that could watch their child and getting a babysitter was more stress. Few parents expressed that they did not want to inconvenience family and friends, while more expressed that they simply did not have anyone who could handle their child. Although they all replied that they felt that their family and friends understood their situation, their stories told otherwise. Many claimed that although their family and friends understood their situation, the family members and friends constantly asked about obtaining a babysitter when events came up on short notice and were disappointed when they could not come out.

One caregiver even admitted to a guilty feeling of having to choose between her friends and her child. One parent spoke of the guilt between choosing to visit family and her own child.

She commented on the complexity of visits to family, and how overwhelming it was for her and her child, but also felt guilty not attending family events. She then told me of a story of when they went to visit in-laws in Oklahoma, and she caught her son climbing out the window at 3am and ultimately, she had to sleep in front of the door on an air mattress to keep him from leaving the room. Although a shocking story to many families with neurotypical children, elopement is common in children with ASD, and this was not the only interviewee that reported such stories. Another mother commented on how after years of turning down invitations to family gatherings, they just stopped being invited. A father addressed the complexity and excess stress of adding other people to their plans, and the guilt of having to cancel or modify plans to accommodate his son if necessary. Other caregivers commented on the rigidity of their child's schedule that did not allow for much socialization.

Additionally, caregivers who also care for typically developing siblings expressed guilt in the time that their child with special needs took away from these siblings. They commented how respite was helpful for this because it allowed them to spend more time with siblings, enhancing family quality of life. One parent commented, "it was great having that respite time because it allowed us time to focus and give our daughter attention, we were able to drop our son off at respite and then spend time doing something that our daughter wanted to do, typically, only my husband gets to engage in these activities, while I am with my son, but because of respite we could all participate together." Many parents with older siblings expressed the intent of never allowing that sibling to assume full responsibility for caring for the child with special needs for an extended time. Although, typically older siblings may babysit younger siblings, they expressed that this was different and did not want any burden or guilt for not assuming responsibility for the sibling with ASD to fall on the typically developing child.

A few parents opened up about having small social circles due their lack of time away from their child. As years go on, the social circle shrinks. One mother talked about her social circle from church, and how slowly the circle disappeared. She told a story of how she knew many families who were close to her from our church. But, as the typically developing kids grew up, they were milestones away from their son, and they just didn't have anything in common anymore. She continued to tell me how they were very close to another family with a boy with special needs; however, then their child went into a group home and although it was a great solution for their family, she just didn't have anything in common anymore. Sadly, she let me know that they were the family that they knew the longest and had the most in common with. She stated that as "their circumstances changed and the other family no longer wanted to spend time with them," which she understood. She said that "they had a lot freer time and wanted to go out, but caring for their son with special needs, they could not." It was a heartbreaking but realistic story of the relationships these caregivers have with others. In the end, most families ultimately commented on a subtheme of loneliness.

Loneliness. One parent went as far to say that, living with a child with autism, leads to "an extremely lonely life." Parents commented that they as their child aged, their social circles started to shrink. One caregiver commented that living with a child with ASD is a "very lonesome very very lonesome, C and I are homebodies anyways but with H we are even more so, it's a very lonely experience." He related this situation to when he visited relatives and compared spending time with his nephews as to speaking Korean because as a parent the difference in the experience was that extreme. His wife commented on the limited access to "quality people that you can trust, just plain and simple," and commented on their limited social network of people that they would need to fly in to watch their son. When caregivers were

questioned about friends, they admitted to being busy, but also isolated. They explained how being a parent to a child with special needs is a 24/7 job, yet there were very little outlets for their frustration.

Feelings of Being Misunderstood and Identity. Even though many parents felt that they had some reliable people in their lives, they continued to discuss how they felt misunderstood, a subtheme to loneliness and limited social network. They expressed frustration with family and friends who thought they might understand what they go through caring for an individual with special needs.

One caregiver discussed being judged in public areas because of different way of responding to his child. He told a story of times out in public, when he was in “lose-lose” situations when his daughter would go into meltdowns, stating,

I felt judged, people were judging me for not reacting to her like a neurotypical developing child, but she’s not, she looks like a typical kid, but then she’ll act inappropriately. People don’t get that, and I think it’s incredibly difficult for me to know that people judge me for being a poor parent because I am not responding in a typical way that you would respond to a typical child. They don’t know that I don’t have a typical child.

This alluded to the parent’s low self-efficacy skills when it came to parenting as a result of these public meltdowns. This public invisible identity was a common theme in the caregivers, as they spoke in comparison to a parent of a child with down syndrome, whom the public eye appears to have more compassion for.

Although many caregivers felt that the cruise experience, and alike experiences, where they spent time with other caregivers with a child with special needs, was easier because there

was more understanding. However, one parent told a different story. She commented on the negativity of this group of caregivers, and how “they have a very bleak kind of outlook on life.” She talked about how she actively avoids these groups and spends less with people who make her feel less anxious. She explained how as a parent caring for someone with special needs, you have such little free time, and how you really need to find positive people in your life to spend this time with.

Cruise Expansion of Social Network. Although not an intention of the interview, all caregivers alluded to the Autism on the Seas respite vacation as part of their interview. They commented first on its ability to bring people together. One caregiver further discussed his comfort level on the respite cruise vacation to be at ease, he said, “You’re with a bunch of people just like us, which while we are the pile of misfit toys everyone’s involved in the same stuff everyone knows.” Many couples referenced that they came on like a couple but left as a family, with multiple couples. Couples, particularly many wives, spoke about how their social networks expanded on social media, and how they continued to keep in contact with other families and follow their journeys.

One mom commented that she saw a lot of similarities between her son and an older boy that they cruised with last. She was happy to keep in contact with this mom, as to look to the next stages of transition that her son would eventually go through and knew who to look to as a support system. The single father spoke about how although he did not come on the cruise to make friends, he ended up keeping in contact with many, as his daughter still hangs out with many of her “cruise friends.”

Parents spoke of being highly comfortable in public spaces on the cruise ship that they might not typically be comfortable in because they not only had support staff to help handle

behaviors, but they also knew they were surrounded by supportive families that would go or had gone through similar “meltdowns” during the period of the week.

Caregiver Well-Being. Caregivers repeatedly discussed the 24/7 exhaustion of caring for a child with autism. They also discussed the extreme benefits of respite and how this was a relief to their stress and increased their quality of life. When interviewing, I found that out of the six couples interviewed, only three caregivers were stay-at home parents, two moms and one dad. When asked about the benefits of respite, all caregivers commented on the time it provides for parents to reconnect with one another.

The positive effects of respite on caregiver well-being is exemplified as one parent shared, “I didn't have to worry, and it gives me a chance to take a deep breath and recharge my batteries again so that I could act appropriately.” And another parent shared that the respite care allowed her time to relax. She stated since there is little time to relax, the respite care allowed her to feel a little at ease, “need time to relax and not think about H, a time to have no concern.”

Even though there were positive aspects of respite care for caregiver well-being, there were also parents who felt uneasy. For example, one parent stated being “apprehensive when you are leaving your child.” Many couples also commented that the first time they were given respite was on the Autism on the Seas cruise experience, and at first, they could not leave their child for the full time because they were anxious and wanted to check in, but in a few days, they took advantage of the respite care. As an observer during this Autism on the Seas cruise experience, caregivers’ attitudes always seem to adjust on the second or third day. They appear to let down a barrier and trust to leave their kids with others while on the first days they appear anxious and stressed.

Couples often commented that because they do not get a lot of time alone with one another, they often provide each other respite. While one parent may be away on a weekend trip with friends, the other is home caregiving for their child. Respite provides the opportunity for date nights or an opportunity for parents to give attention to another sibling. During respite, caregivers commented that they were not worried about their child and could relax.

Parents repeatedly talked about having time for themselves, like “it was a huge game changer for us, what? Dinner together that’s crazy,” “it *gives us time to decompress*,” and, even having an hour to themselves due to respite care was also important for well-being. One parent commented on what it’s like for him and his wife to not be able to think about their child and relax: “It’s something that we can never do.” He commented that him and his wife always have to be 24 hours on guard and not being able to think about that is an amazing thing even if it's just for an hour. Another parent commented that his favorite part of the cruise was when he got to go out with two to three other couples and eat with other adults. He described it as a rarity.

Many couples discussed on struggling to connect with one another with the constant 24 hour demands on their child. One parent compared it to tensing a muscle and how without reconnecting the difficulty of tensing that muscle becomes even more difficult.

One of the most powerful quotes gained from these interviews came from a stay at home mother when questioned about any additional comments with regards to respite, she stated:

Just that you don’t realize how much you need it until you have it, it’s incredibly worthwhile and you don’t realize how incredibly exhausting and this makes me teary, how exhausting daily life is (SOBS) and you have little breaks, but you need everything”

Overall, caregivers were positive about respite, and shared many experiences of its positive effect on their well-being.

Child Well-being. Caregivers also mentioned the benefits of respite on their child's well-being. Although as caregivers they enjoyed the relief that respite provides, they also felt that the child benefited from the break of being with that caregiver during respite sessions. Caregivers seemed to believe that their child was in a better mood after respite sessions. Other sub-themes that arose were child benefit from the exposure to different types of kids, and exposure to different people and different ways of doing things and facilitating independence.

Exposure to different types of kids. Caregivers commented on the benefits of their child being exposed to different types of kids. Many commented on how their children learned to be friends with different kids with different needs and recognized the flexibility that they needed to exert. One father commented on the benefits to his typically developing daughter in attending respite sessions, stating that it was great that she didn't see disability, only that sometimes people have a "difficult time." He also commented that his son with ASD learned to accept other kids with special needs, instead of being set off by their behaviors.

Exposure to different people and different ways of doing things. Caregivers emphasized the importance of their child interacting with different people. Multiple caregivers highlighted that their child barely gets to spend time outside the family besides school activities, and how this was a great way for them to have their own time with their friends and new people. The single father also commented about how because his daughter is exposed to working with so many different staff during respite, that she learns greater flexibility and to adapt to different coping strategies. He stated that typically she is only used to one therapist but here in the respite setting, she was forced to adapt to others.

Facilitating Independence. Respite sessions were facilitating independence and their own time away from the family. Parents of older children particularly commented that they felt

that their kids needed a break from them as parents as typically developing teenagers do. One father commented about how important it is for his son to have activities on his own, and not be bound to the restraints of family activities, “it provides independence and preference.”

Severity and Respite Programs. Symptom severity and its effect on the design of ideal respite programs was another theme that arose. However, no matter the severity of the child’s symptoms, each parent’s priority was the staff. Caregivers mentioned that staff should be screened, trained, and have degrees and experience in working with the specific population. One parent commented that, “respite is great, but you have to have the right person in place.” Another caregiver commented on the quantity of staff that was able to help engage and facilitate relationships within a respite session. Caregivers expressed desire for staff members who could pick up on cues and assess the kids without being invasive, dismissive, or negative.

Although all caregivers agreed that the priority was the staff, the interviews went differently when asked about the structure of the respite sessions. After analysis, it appears to have differed based on the severity of ASD behaviors/ tendencies and communication impairments. I noticed that caregivers of individuals with more severe behaviors expressed a desire for private respite provided at their house in a 1:1 ratio, while caregivers of individuals with more mild behaviors expressed a desire for a more inclusive community respite with typically developing siblings and more opportunities for socialization. Although caregivers of individuals with more severe behaviors discussed the importance of socialization, they ultimately felt that their child was interested in what he or she was interested in, and during respite time, safety and keeping them happy was the priority over social skills. Of course, all caregivers also commented on a safe environment that was elopement proof.

Consistent categories arose when interviewing the different parents. These categories included staff, structure, population, equipment/ logistics, parental education and safety. Staff related aspects discussed were background in working with population, screened, trained, have degrees, good demeanor, work well with my kid, good person.

Desired structure and some level of formality for ideal respite program included a minimum of 2-3 hours at a time and something that was local in community. Other desired aspects included having services that could accommodate different cognitive/language ability levels and age groups. Equipment/ Logistics aspects involved sensory appropriate toys allowing individuals with varying special needs to be stimulated in differentiated activities and an environment that offer challenges and activities for varying levels of child severity. Parental education was another key aspect that arose when talking to the single parent. This parent stated that it would be beneficial to receive parent training while his child is at respite. And the last aspect was safety. Elopement was a prominent concern for the married couple when imagining a realistic respite for their son.

CHAPTER V

Discussion

The present set of studies used a mixed-method design to investigate the effects of respite on caregivers of individuals with ASD. Analysis of the quantitative data from parents' responses to questionnaires allowed for the investigation of the effects of a respite vacation on various indices of caregiver well-being, as well as the pattern of association between caregiver well-being and aspects of respite utilization. The interviews from the qualitative component of the study gave voice to the caregivers' perspectives on parenting a child with special needs; from these interviews I gained knowledge of caregivers' experiences with respite, including factors that promoted and impeded their use of respite. While it was heartbreaking to hear about the negative effects of having a child with ASD on caregiver well-being, it was important to hear about the benefits of respite on their well-being as such information can help inform the design of future programs to support individuals with disabilities and their families.

Summary of Findings

Overall the quantitative study found positive associations between caregiver self-efficacy and social network and between social network and quality of life. Thus, on average, parents who reported a greater social network also tended to report higher self-efficacy and a higher quality of life. On the other hand, a negative association was found between stress and family quality of life, social network and self-efficacy; thus the more stress caregivers tended to report, the lower their quality of life, social network and self-efficacy. These findings are correlational, and a direction of causality cannot be ascertained. However, one might speculate that as parents interacted with other parents and were given more opportunities to socialize with others (i.e., higher social network), their confidence in their parenting abilities may have increased (i.e., self-

efficacy). Additionally, as these social opportunities increased, it is possible that caregivers were given more opportunity to interact with others, thus explaining an increase in their quality of life.

The study also found an unexpected negative correlation between social network and self-efficacy. It is possible that parents with a larger social network have lower self-efficacy because they are comparing themselves with more parents. A closer examination of social network would be needed to better understand this correlation. One would need to determine whether the social networks these caregivers are engaged in are generally more positive or negative. Additionally a negative correlation was found between self-efficacy and severity, indicating that caregivers of children who need greater support have higher self-efficacy. This result could relate to the issue of severity as it influences parents' experiences with their child or their perception of disability. Self-efficacy could also be related to the consistency of a child's behavior. These issues will be addressed in greater detail below, overall, these links, and their connection to past literature, are explored in greater detail in the discussion that follows.

An important contribution from the quantitative component of this study was its description of caregivers' reports of respite and self-care activities. Caregivers reported that they were given time to themselves "less than monthly," when discussing caregiver self-care. This is significantly less than the reports of caregivers of typically developing children, which suggest that parents of children with disabilities experienced more caretaker and family burden (Sanders & Morgan, 1997). Caregivers of individuals with autism perceived more stress with regards to time demands and family opportunity (Sanders & Morgan, 1997). The study suggested caregivers of children with special needs have a more difficult time finding childcare or respite services. It has also been shown that families with children with autism have less energy (due to severe behaviors and unusual sleep patterns) to engage in a productive use of free time (Saunders

& Morgan, 1997). This is important because caregivers of ASD are given less time to themselves; their overall well-being is severely affected (Sanders & Morgan, 1997). Furthermore, when asked about the number of activities the child with special needs attended outside the house, caregivers in the present study reported that their children “seldom” to “occasionally” attended activities outside the house. This could correlate with an overall impaired well-being of a caregiver (Sanders & Morgan, 1997).

Overall, findings from the qualitative study revealed the difficult reality of being a caregiver of a child with special needs. Although the quantitative aspect of the study indicated many non-significant findings with regards to pre versus post intervention outcomes, the qualitative study strengthened this aspect of the mixed methods study. Many of findings that emerged from the quantitative study regarding caregivers’ high stress levels, low sense of self-efficacy, limited social network and overall low family quality of life. Most importantly, several themes emerged from the qualitative findings that indicated areas on which future research may need to focus in the design and delivery of future effective respite programs. These themes include the notions of caregiver trust of respite service providers, caregivers’ sense of loneliness within their social lives, and caregivers’ loss of identity.

Stress

Results of this study revealed that the reported stress levels of caregivers of children with ASD were slightly above the normal range of stress relative to the measure’s normative sample. Caregiver interviews revealed a similar pattern of high stress as caregivers repeatedly discussed the constant exhaustion of caring for a child with ASD. In terms of the association between stress and other indices of well-being, on average, parents who reported more stress also reported decreased family quality of life, social network and self-efficacy. These findings are consistent

with past research indicating that parents of children with ASD experience higher levels of stress than parents of children with any other condition (Phelps, 2009). Moreover, consistent with findings from this study, past research has indicated that stress impairs health in numerous ways, and alters an individual's perception of his or her life (quality of life) and confidence in his or her parenting skills (self-efficacy), and often limits social opportunities (social network).

Specifically, high levels of parenting stress have been shown to correspond with less optimal parenting behaviors (Hassall, Rose, & McDonald, 2005; Hastings & Johnson, 2001; Tomanik, Harris, & Hawkins, 2004). The Effects of the Situation Questionnaire (Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998) revealed seven themes including psychological implications, familial implications, social implications, services, spiritual benefits, economic challenges, and focus on the future of having a child diagnosed with autism (Phelps, 2009).

Together, findings from the present study suggest that when designing respite programs, it is ideal to utilize methods that would decrease caregiver stress, and thus increase optimal parenting behaviors. The growing research on mindfulness has also been extended to parents of children with special needs and can be one possible avenue for future respite programming designed to improve parent well-being. For example, a review of mindfulness-based interventions on caregivers of individuals with intellectual or developmental disabilities may be useful. Results indicated that increased mindful awareness, increased cognitive diffusion and reduced thought suppression were paired with improved caregivers' ratings of distress (O'Donnchadha, 2017).

In thinking about the future of respite programs, and the effectiveness of mindfulness interventions, future respite programs may wish to connect the two. During times of respite, when children with special needs are being care for by other staff, therapist could integrate

mindfulness interventions into parent-focused classes. Respite would allow parents the time to obtain this therapy and the mindfulness interventions may be beneficial in improving parenting well-being.

School-based resources (parent-teacher alliance, and consultation intervention) could also help reduce parent stress (Krakovich, et. al, 2016). The study concluded with different predictors of stress in caregivers of children with ASD, depending on whether the stress stemmed from parent-related stress or perceptions of child-related demands. It was also shown that school-based child focused interventions, parent-teacher alliance and internal and external resources were all contributors to caregiver stress.

The effectiveness of school-based resources in reducing parent stress is another technique in which can be connected to respite to improve overall parent wellbeing. During respite sessions, parents could participate in school-based meetings. This may allow parents to feel more included in their child's educational process, and feel that this process is collaboration between home and school. If school counselors assisted during this respite time by communicating with parents, and focusing on a consultation intervention similar to the study on school-based resources, caregivers may be relieved of stress (Krakovich, et. al, 2016). Autism on the Seas incorporates a consultation like setup with regards to its parent intro sessions during the first night of the cruise. These parent intro sessions are highly recommended, and allow caregivers to meet with specific staff designated as that family's liaison. This allows caregivers to give more information than what was previously written on the pre-cruise questionnaire about their child and also allows them to get to know the staff member in a more intimate setting. This promotes a parent-staff alliance, similar to successful interventions noted in previous research.

Family Quality of Life

Family quality of life has become an increasingly important topic of research, because it reflects not only the individual with special needs but also the well-being and perceptions of the entire family, which can ultimately have direct and indirect effects on individuals' well-being. On average, participants in the present study rated their quality of life as "less than satisfied." Parents of children with ASD showed significantly less QoL as compared to other groups with special needs (Mugno et al., 2007). Families with ASD have been found to restrict their social life and making choices negatively impacting QoL. In other words, the choices families make to best fit their child with special needs is not necessarily the best choices for the overall family, thus leading to a decreased quality of life (Allik, Larsson, & Smedge, 2009).

Forty-three preschoolers with autism and 28 typically developing preschoolers were studied during emotion regulation strategies used during low-level stress tasks (Nuske et. al, 2017). Parents in this study were then asked to report on their quality of life and family functioning, and their child's internalizing and externalizing behaviors. The study concluded that more externalizing behaviors predicted lower family quality of life. Findings from this study suggest that families with poor meta-emotional regulation strategies have children with more undesired behaviors that are linked to lower family quality of life.

Previous studies could be informative to the design of future respite studies. Specifically, one study consisted of three groups, an experimental group (n=7) with respite care services only, an experimental group with a multifaceted family support program in addition to respite care services (n=7), and a control group with no support (Sung & Park, 2012). The multifaceted family support system consisted of recreational programs, counseling and social support coordination. Although there was no difference in parenting stress between the groups, results of

this study reflected a difference in family quality of life between the multifaceted family support program and the control group (n=7). It may be that the additional opportunities provided did not change the stressors associated with parenting a child with autism but did have additional benefits on the overall wellbeing of the family.

Autism on the Seas is a unique respite program, in that it provides staffed support to individuals with ASD and their families to enjoy activities together. The program also allows typically developing siblings to join respite drop off activities, thus families do not have to restrict their social life once onboard. The Autism on the Seas program focuses on staff supporting families' activities in addition to providing daily respite. It should be a priority to incorporate this well-being factor when designing respite programs because respite affects the entire family. While Autism on the Seas staff do not provide direct training to caregivers with regard to techniques that could help support their children, staff are frequently modeling emotion regulation strategies and other techniques that, if used by parents, may improve the overall family quality of life.

Respite provides time away for the individual, thus giving caregivers a break, individuals with special needs an opportunity to build independent skills, and siblings an opportunity to spend more individualized time with their caregivers. The Autism on the Seas program can be considered similar to the multifaceted family support program in Sung's study, rather than just a respite service, because it provides a multi-disciplinary support plan- emphasizing on expanding social network, self-efficacy, stress and family quality of life.

Social Network

Results of the study indicated that loneliness was a major issue for the participants, as many caregivers with ASD reported feeling isolated. During the interviews, caregivers reported

that respite was important to their wellbeing, and emphasized its positive effect on their life. On average, caregivers in the present study reported that they had social networks that included between two to five individuals and that they attended events between once per year to every few months. This pattern was also found within the interviews when caregivers expressed the difficulty in finding a trusted caregiver and having a limited social network. Social network is important for all caregivers, but especially imperative for caregivers with children with special needs. These caregivers often a smaller social network because they feel judged and alone. Previous research has shown a lack of social support for caregivers of children with ASD (Sanders & Morgan, 1997). Because caregivers of children with autism and caregivers of children with Down syndrome view their child as having negative behaviors, these families might be more socially isolated (Sanders & Morgan, 1997). These families may experience more feelings of stigmatization and the study suggests that the strong feelings that caregivers with autism experience with regards to the severe behaviors causes these caregivers to be more withdrawn and make less effective use of social supports and outside activities that may alleviate stress (Sanders & Morgans, 1997).

In a study of the effect of children's health and treatment status and parent coping, depression, anxiety and anger, the results of this study indicated that parents who received more social support had lower scores of depression, anxiety and anger (Gray & Holden, 1992). Moreover, low social support has been reported to be the most powerful predictor of increased stress in parents (Gray and Holden, 1992). Thus, methods that increase social support would be beneficial to relieving the stress of these caregivers.

In the present study, interviews revealed that caregivers often limited their own social network because of the guilt they felt when leaving their child and taking time to themselves to

decompress. Guilt was also expressed with respect to the need to care for another sibling. Caregivers' social networks were also limited because they reported feeling isolated and misunderstood by their friends and family. Caregivers reported that while parents of typically developing children celebrated milestones together and went out routinely with their friends, these caregivers of children with special needs simply felt that they could not take this time away from their child. Additionally, caregivers reported that the milestones celebrated were misaligned, and caused them to feel heartbroken rather than proud. Caregivers reported feeling judged, alone and isolated themselves to an extremely restrictive and routine life because it was easier for their child.

This information is important for the design of future research and programming aimed at improving the well-being of caregivers of individuals with ASD. First, in the future, it would be beneficial to study the contexts in which caregivers of individuals with ASD are most likely to socialize. Past research has found that a lack of social support can lead parents to withdraw from the larger community (Sanders and Morgan, 1997). When individuals are given more opportunities to socialize outside of their immediate family, they feel more supported and report feeling less depression, anxiety, and anger (Boyd, 2002). In the present quantitative study, a negative correlation was found between self-efficacy and social network. This correlation should be investigated further; for example, there is a need to understand who makes up these social networks and the type(s) of support that are being provided. When designing respite programs, it would be helpful to facilitate the building of a social support system for caregivers and siblings. A program for siblings would help alleviate caregiver guilt and social groups with other caregivers that identify as a struggling parent with a child with special needs may help these caregivers feel more emotionally supported and less isolated and judged. The Autism on

the Seas respite vacation arose in numerous interviews with caregivers in the present study as a good form of social network, but it is critical to expand such programs such that caregivers may come together to support each other socially and emotionally. Past research has found that caregivers with children with autism benefited from parent to parent support (McCabe, 2008). In this qualitative study, the authors interviewed caregivers of 43 children with autism and found that they benefited from parent to parent support because they were able to learn from each other and to gain moral support and encouragement in a relationship that is more equal and less discriminatory than was experienced from others in their community (McCabe, 2007). The authors also tested the mediating effect of formal and informal social support on the relationship of caregiver burden and quality of life and found that an informal social support network can be helpful in decreasing caregiver burden and enhancing QOL in parental caregivers' lives (Marsack & Samuel, 2017). Overall, interventions aimed at facilitating social support are likely to reduce stress.

Autism on the Seas is a good model for a respite program that is likely to increase social support. The organization incorporates parent meet ups into the schedule. During these events, individuals with special needs and siblings are at respite with staff, and it is only suggested that parents meet at the selected location. A dinner during respite is also a way in which the organization facilitates an informal social support. There is no staff facilitating these events but only suggesting a meet up location. Formal supports that Autism on the Seas incorporates include organizing social media pages for individual cruises, parent connect (a tool that new parent cruisers can use to connect to experienced parent cruisers), and open communication connections with staff members after the sailings. Autism on the Seas also does its best to distribute their cruise schedule onboard, and advertise any promotions available for booking

onboard. This has led to families onboard together booking other vacations together or forming their own staffed cruise if the date they desire is not yet on the organization's schedule. Although data was not formally taken on all these aspects of the organization in this current study, it can be done so and incorporated into future programs.

Parent Self-efficacy

In the present study, caregivers' reported low self-efficacy. It was thought that the respite vacation intervention would improve self-efficacy because it would present caregivers with new strategies utilized by cruise volunteer staff and present them with opportunities for their family to succeed in novel environments. Caregiver self-efficacy beliefs are a powerful predictor of positive parenting practices and a mediator of some of the most thoroughly researched correlates of parenting quality including maternal depression, child temperament, social support, and poverty (Coleman & Karraker, 1997). Thus, it is imperative that any program that aims to support parent well-being targets caregivers' sense of self-efficacy.

Parenting self-efficacy is inversely related to levels of parental stress and depression in mothers of children with ASD (Kuhn & Carter, 2006). During the present study's interviews, caregivers expressed comfort in cruising with caregivers of children with needs similar to those of their own children because it allowed them to feel as part of a group and not isolated. Parents reported feeling more confidence, as they felt less judged. This highlighted a benefit of the Autism on the Seas respite vacation program. The design of respite programs, which assist in promoting higher self-efficacy, would be extremely beneficial to the well-being of any caregiver. A review of self-efficacy and parenting quality discussed different interventions with regards to self-efficacy and found that self-efficacy interventions could be more successful if they structure

opportunities for success within parent-child interactions (Coleman & Karracker, 1997). The reviewed interventions include therapies on behavioral, marital, and family therapy aimed at changing family cognitions (Mash & Johnston, 1990) as well as interventions that instruct caregivers about effective communication with their child (Barnard, Morisset & Spieker, 1993). Other interventions that have been deemed effective incorporate teaching inexperienced caregivers about the behavioral organization of children (Barnard, Morisset & Spieker, 1993). The study concluded with suggested parental history antecedents and current factors likely to influence parenting self-efficacy (Coleman & Krarrcker, 1997). These factors include attachment to primary caregivers in family of origin, ecological conditions in family or origin, cognitive/behavioral preparation for parenting, experience with children, child factors, current ecological conditions, and parental factors.

In thinking about designing a respite program that also supports parent self-efficacy it would be beneficial to deliver parent training during some respite sessions. Caregivers could have the opportunity to not only learn about the techniques best utilized with their child but also be presented with the opportunity to see and experience hands-on therapy with the trained professionals that deliver respite. Therapy sessions may also be warranted during respite sessions to not address parenting techniques but the negativity that these caregivers may have in the faith of their own abilities. Once parents become familiar with the optimal parenting practices and feel able to deliver these, they may develop a stronger sense of competency within their parenting role and increase higher self-efficacy. Additionally, considering the qualitative interviews, it should be noted that respite should take place in a welcoming environment where caregivers do not feel judged. Autism on the Seas promotes a community culture, where they have already educated the cruise staff, and their staff, and families do not feel judged. The

organization also promotes individuals with special needs trying novel activities (dining in a formal dining room, rock climbing, ice skating) with the assistance of their professional staff. This may inform caregivers of new hobbies for their child and more importantly give them new techniques to use at home with their child during these activities.

Observations of the Researcher

As a professional with over 16 years in the special education field, not only as a group leader and researcher but also a teacher, and camp counselor, there are several observations that I made after getting to know all the children of caregivers interviewed in the qualitative study. I have cruised with Autism on the Seas for the past 9 years, totaling more than 20 cruises ranging from five to nine days each, and have worked with hundreds of individuals with Autism Spectrum Disorder. I cruised with all but one family in the qualitative study (who I met and spent time with them during a fundraiser). Children of the caregivers in this study had a range of ages and severity. One thing I noticed was that there was a discrepancy between husbands and wives in many of their reported symptom severity scores. Moreover, after considering my own experience within the field, I disagreed with many of the severity classifications reported by parents. Two thoughts come from these observations. First, I do not have complete confidence in these scores as reported by parents. Second, the disagreement between parents (and between parents and myself) is interesting in its own right and points to a possible area of future research. Severity is related to one's perception of disability, and greatly dependent on a parent's views not only of his or her child, but also other children with and without special needs. Such perceptions may have direct or indirect implications for parents' well-being and their interactions with their children with disabilities. In addition to parent bias, it should be noted that the severity scores within the present study may not accurately reflect children's symptoms. In the

present study severity and parenting self-efficacy were negatively related. This could indicate that caregivers of the children in need of more support gained more training and felt more confident in caring for their child. It could also indicate that children with less severity needed less consistent supports in varying community settings and caregivers felt less prepared to handle this and thus had lower parenting self-efficacy. It is important for future research to explore these notions using data from multiple family members, including siblings and extended family. Lastly this study was only an initial step in understanding the role of severity, future studies should use a standardized measure such as the Childhood Autism Rating Scale (CARS) or Autism Diagnostic Observation Scale (ADOS).

Another observation I made through this study was that, based on my own classification of severity scores, caregivers of children with more severe behavior and communication deficits seemed resistant to send their children to respite programs during the vacation. It may be that because their child's communication was particularly impaired, they believed their child may not be able to communicate the events that take place while away from their caregiver; this could add to the concerns that caregivers have about leaving their child with others and preclude them from taking advantage of the programming available for their child.

Based on my own impressions of severity, I noted that caregivers of children with less severe behavior and communication deficits seemed to more often be neglected from receiving government support, and often on the constant search for new programs that may fit their child. While caregivers of more children with more severe behavior and communication deficits were quicker to compare respite to babysitting services and a break for their child, caregivers of children with less severe communication deficits and behaviors described respite as more therapeutic. Future research should utilize a more specific severity scale with input from health

providers who may be less bias than caregivers when rating the behavior and communication of the child.

Finally, it is important to note that the discussion of respite at hand is best suited for caregivers of individuals with moderate to severe disability. The majority of children serviced by the Autism on the Seas respite vacation are children who cannot be serviced by the typical kids' club on the cruise lines. The ratio of Autism on the Seas requires 1 staff to 2 children, while the typical children's club only requires 1 staff to 4 toddlers and a higher ratio with any children older than toddler age. In the current study, there is no way of knowing the severity of the child reported on in interviews, or if they even attended Autism on the Seas events. As such, future research should explore how severity interacts with parents' beliefs and utilization of specific types of respite programming.

Limitations and Future Research

Despite the many strengths and the noted contribution made by the mixed-method design of this study, there are several limitations that offer important directions for future research. One limitation of the study was the fact that it did not explicitly include a measure of parents' perception of disability, which is a component of ABCX theoretical model. Specifically, according to ABCX, caregiver perception of disability and their preception of the demands they are faced in caring for their child with special eneds, play a role with their response to disability, including the resources they seek out and are provided and how the "crisis" unfolds in their family. Disability perception can be interpreted in multiple ways and is often a characteristic that is not stagnant within a caregiver's life. Currently there is limited research on measures that adequately measure caregiver disability perception. This may be a particularly fruitful direction

for future research. For example, it is possible that disability perspective changes throughout the varying phase of the child's life, and is also affected by the disability community. Future research should aim to examine such perspectives longitudinally, to understand the trajectory of such perspectives for caregivers of children with disabilities of varying severity levels, and whether such trajectories are related to caregiver well-being over time.

Another limitation of the study is related to the potential that it included recruitment bias. The study examined respite and well-being among parents who participated in one type of respite program (i.e., the participants were all selected from a group of caregivers who cruised with the Autism on the Seas organization) and their participation was voluntarily. Together, these limitations negatively impact the generalizability of our findings. It will be important for future research to examine respite behaviors in varying types of programs. The study sample size was also a limitation, and several analyses may have been underpowered as a result of the small sample. Future studies should aim to target a larger population. Finally, it will be important for future research to include measures of well-being that are not all self-reported.

Additionally, the researcher cruised with the majority of families interviewed, thus giving a case for bias. This is significant in that the implication of increased respite could be a vital key component to a caregiver's well being. Caregivers can then experience a decrease in stress and thus a healthier life both physically and psychologically for these individuals, thus leading to an improved quality of life for individuals with autism.

There was also a limitation in the study's assessment of differences in caregivers' reports of well-being before, and three months after, their sailing on the Autism on the Seas respite vacation when controlling for child characteristics. Thus, the timing of data collection may have impacted some of the findings. For example, it is possible that the short three-month window

was not sufficient to show change in indices of well-being including stress, social network, self-efficacy and family quality of life. All results of these analyses showed no significant improvement in parent well-being from pre test to post test (i.e., post-cruise surveys were given 3 months after caregivers disembarked the cruise ship). Moreover, the Autism on the Seas respite vacation intervention itself ranged in duration (i.e., 5-9 days), which may have been too little time to make a life-changing difference in well-being post-cruise.

Another limitation was that there was a discrepancy in reports of severity between pre and post surveys reported by caregivers, requiring analyses to be conducted utilizing an average between the two severity scores. In the short demographic surveys with interview participants there were also discrepancies in severity as described by two parents caring for the same child. Although a methodological limitation, this finding is also interesting and should be explored in future research. Future studies may choose to utilize a standardized measure to confirm the ASD diagnosis.

Future work should also explore the definition of respite in greater depth. While the researcher asked the definition of respite to the interview participants, it may be that variability in participants' definitions of this notion could contribute to their responses and that some participants may have overlooked benefits of the service. It would be interesting to study duration and frequency of respite and the lasting effects of each. A similar study could also take place, where caregivers are asked to keep a daily dairy entry on the process of receiving respite every evening.

Implications and Recommendations

The results of the present studies suggest that the types of experiences offered by respite are valuable for caregivers' wellbeing. When thinking about designing an effective respite

program, this study reinforces the importance of focusing on specific interventions to treat caregivers' wellbeing while also providing opportunities for caregivers to get breaks from their parenting role. The four caregiver well-being variables examined in the present study were all interrelated, thus the ideal respite program would be designed to integrate all the techniques discussed above. Stakeholders should first focus on developing a program based on trust by hiring highly qualified professional staff. Staff should be multi-disciplined and inclusive of teachers, counselors, and therapists, and have proficiency in not only working with the individuals with special needs but more importantly the caregivers. The respite program should be multi-faceted consisting of recreation programs, counseling and social support coordination. Ideally, a multi-disciplined staff should be recruited, who can address school-based interventions, individual consultation, mindfulness-based therapy, and parent training. The ideal respite program would incorporate the entire family inclusive of siblings, and take on a very holistic approach. Respite sessions would be transparent with caregivers, and host events corresponding to these events where caregivers could socialize informally. The respite program would target decreasing caregiver stress, increasing family quality of life, increasing caregiver social network and increasing caregiver self-efficacy. When these four wellbeing variables are addressed, caregivers can benefit in their own wellbeing and thus be able to better care for their child.

Conclusion

Currently, ASD affects a growing number of individuals each year, and although many new programs are being developed to support individuals with ASD and their families, it is imperative that these respite programs be built based on research identifying the most

meaningful way to increase caregiver well-being. Previous studies have demonstrated that respite sessions must be part of a multifaceted family support program to improve caregiver well-being variables. Programs of this nature are rare. Organizations need to focus on building trust with caregivers and being explicit in the services families are offered in addition to respite. A further understanding of how such programs are related to caregiver well-being and what barriers caregivers experience would help inform the design of more accessible and effective respite programs.

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Appendices

Appendix A: Study 1 Questionnaire

Section A: Demographics

Section B: Severity of ASD and Social Communication Disorders

Section C: Participation Rates

Section D: Self-Care Assessment

Section E: PSI: Short Version

Section F: SNI- Berkman-Syme Social network Index

Section G: Family Quality of Life Survey (Beach)

Section H: Self-efficacy for Parenting Tasks Index (SEPTI)

Section I: Post- Cruise, Participation in AotS activities

Section A:

Demographics

1. Age:
2. Ethnicity:
 - a. White
 - b. Hispanic, Latino, or Spanish origin
 - c. American Indian or Alaska Native
 - d. Black
 - e. Asian or Pacific Islander
3. Region of Residence:
 - a. Northeast America
 - b. Southeast America
 - c. Northwest America
 - d. Southwest America
 - e. Central America
 - f. Outside USA
4. Marital Status:
 - a. Currently Married/ Committed Partnership
 - b. Widowed
 - c. Divorced
 - d. Separated
 - e. Never married/partnered
5. Income:
 - a. Less than \$20,000
 - b. \$20,000 to \$34,000
 - c. \$35,000 to \$49,000

- d. \$50,000 to \$74,999
 - e. \$75,000- \$99, 000
 - f. \$100,000- \$149,999
 - g. \$150,000 to \$199,999
 - h. 200,000 or more
6. Number of Children:
 7. Number of Children with Special Needs:
 8. Relationship with individual with special needs:
 9. Age(s) of Child(ren) with Special Needs:
 10. Formal diagnosis of Child with Special Needs:
 11. How did you find out about Autism on the Seas?
 - Through an organization
 - Through a friend
 - Through an online search
 - Through social media

*If you have more than one child with special needs, please complete the remainder of the survey as it pertains to only the oldest child with special needs.

Section B

Instructions: Please read the following levels of functioning that describe children’s social communication behaviors and repetitive/restricted behaviors. Think about your child with special needs. Please check the level that best describes your child.

Official Diagnosis: _____

	Level 0	Level 1	Level 2	Level 3
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<p>Social Communication Deficits:</p>	<p><input type="checkbox"/> None</p>	<p><input type="checkbox"/> Mild Requiring Support (i.e.; Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples or atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.)</p>	<p><input type="checkbox"/> Moderate Requiring SUBSTANTIAL support (i.e.; Marked deficits in verbal and nonverbal social communication skills; social communication skills apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.)</p>	<p><input type="checkbox"/> Severe Requiring VERY SUBSTANTIAL support (i.e.; Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.)</p>
<p>Restricted Interests and Repetitive Behaviors:</p>	<p><input type="checkbox"/> None</p>	<p><input type="checkbox"/> Mild Requiring Support (i.e.; Rituals and repetitive behaviors (RRBs) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRBs or to be redirected from fixated interest.)</p>	<p><input type="checkbox"/> Moderate Requiring SUBSTANTIAL support (i.e.; RRBs and/or preoccupations and/or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when</p>	<p><input type="checkbox"/> Severe Requiring VERY SUBSTANTIAL support (i.e.; Preoccupations, fixed rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect</p>

			RRBs are interrupted; difficult to redirect from fixated interests.)	from fixated interest or returns to it quickly.)
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Section C: Please check the category that applies to your child's participation in leisure activities.

	Frequently	Occasionally	Seldom	Never	Not Sure
Watching television					
Playing games					
Walking for pleasure					
Reading books for pleasure					
Competing in team sports (for example: soccer, baseball, basketball, etc.)					
Competing in individual sports (for example: tennis, ping pong, swimming, etc.)					
Going out for the evening					
Bicycling					
Going to the movies					
Visiting art					

galleries or museums					
Listening to music					
Collecting or making something					
Attending sports events					
Attending performances					
Surfing the web					
Working on the computer					
Other: _____ _____					

Section D						
Instructions: Over the last 30 days how often did you:						
		Never	Less than Monthly	Monthly	Weekly	Daily or Almost daily
D. 1	Spend time apart from your children	1	2	3	4	5
D. 2	Pursue a social activity with a partner/spouse/friend	1	2	3	4	5

D. 3	Leave the house without your children with you	1	2	3	4	5
D. 4	Pursue personal hobbies and interests that extend beyond parenting (e.g., gardening, reading a book, watching a movie, playing sports, arts and crafts, etc.)	1	2	3	4	5
D. 5	Read literature that is unrelated to parenting or work	1	2	3	4	5

Section E						
Instructions: Please circle the answer that best represents your current feelings.						
		Strongly Agree (SA)	Agree (A)	Not Sure (NS)	Disagree (D)	Strongly Disagree (SD)
E.1	I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
E.2	I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD

E.3	I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
E.4	Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
E.5	Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
E.6	I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
E.7	There are quite a few things that bother me about my life.	SA	A	NS	D	SD
		Strongly Agree (SA)	Agree (A)	Not Sure (NS)	Disagree (D)	Strongly Disagree (SD)
E.8	Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).	SA	A	NS	D	SD
E.9	I feel alone and without friends.	SA	A	NS	D	SD
E.10	When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
E.11	I am not as interested in people as I used to be.	SA	A	NS	D	SD
E.12	I don't enjoy things as I	SA	A	NS	D	SD

	used to.					
E.13	My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
E.14	Most times I feel that my child does not like me and does not want to be close to me.	SA	A	NS	D	SD
E.15	My child smiles at me much less than I expected.	SA	A	NS	D	SD
E.16	When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
E.17	When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
E.18	My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
E.19	My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
E.20	My child is not able to do as much as I expected.	SA	A	NS	D	SD
E.21	It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD

E.22	I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
E.23	Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
E.24	My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
E.25	My child generally wakes up in a bad mood.	SA	A	NS	D	SD
E.26	I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
E.27	My child does a few things which bother me a great deal.	SA	A	NS	D	SD
			Strongly Agree (SA)	Agree (A)	Not Sure (NS)	Disagree (D)
E.28	My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
E.29	My child gets upset easily over the smallest thing.	SA	A	NS	D	SD
E.30	My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD

E. 31	There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
E.32	My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
E.33	My child makes more demands on me than most children.	SA	A	NS	D	SD
E.34	For the next statement, choose your response from the choices “1” to “5” below.					
	<p>I feel that I am:</p> <p>1 Not very good at being a parent</p> <p>2 A person who has some trouble being a parent</p> <p>3 An average parent</p> <p>4 A better than average parent</p> <p>5 A very good parent</p>					
E.35	For the next statement, choose your response from the choices “1” to “5” below.					
	<p>I have found that getting my child to do something or stop doing something is:</p> <p>1 Much harder than I expected</p>					

	<p>2 Somewhat harder than I expected</p> <p>3 About as hard as I expected</p> <p>4 Somewhat easier than I expected</p> <p>5 Much easier than I expected</p>					
E.36	For the next statement, choose your response from the choices “10+” to “1-3.”					
	<p>Think carefully and count the number of things that your child does that bother you. For example: dawdles, refuses to listen overactive, cries, interrupts, fights, whines, etc.</p>	10+	8-9	6-7	4-5	1-3

Section F: Please answer the follow questions.

<p>1. How many close friends do you have? Close friends are people that you feel at ease with/ can talk to about private matters.</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> 1 or 2</p> <p><input type="checkbox"/> 3 to 5</p> <p><input type="checkbox"/> 6 to 9</p> <p><input type="checkbox"/> 10 or more</p> <p><input type="checkbox"/> Unknown</p>
<p>2. How many of these close friends do you see at least once a month?</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> 1 or 2</p> <p><input type="checkbox"/> 3 to 5</p> <p><input type="checkbox"/> 6 to 9</p> <p><input type="checkbox"/> 10 or more</p> <p><input type="checkbox"/> Unknown</p>

3. How many relatives do you have, people that you feel at ease with/ can talk to above private matters?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

4. How many of these relatives do you see at least once a month?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

5. Do you participate in any groups, such as a senior citizen, social or work group, religious-connected group, self-help group, or charity, public service, or community group?

- No
- Yes
- Unknown

6. About how often do you go to religious meetings or services?

- Never or almost never
- Once or twice a year
- Every few months
- Once or twice a month
- More than once a week
- Unknown

7. Is there someone available to you whom you can count on to listen to you when you need to talk?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

8. Is there someone available to give you good advice about a problem?

- None
- 1 or 2
- 3 to 5
- 6 to 9

<input type="checkbox"/> 10 or more <input type="checkbox"/> Unknown
9. Is there someone available to you who shows you love and affection? <input type="checkbox"/> None <input type="checkbox"/> 1 or 2 <input type="checkbox"/> 3 to 5 <input type="checkbox"/> 6 to 9 <input type="checkbox"/> 10 or more <input type="checkbox"/> Unknown
10. Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)? <input type="checkbox"/> None <input type="checkbox"/> 1 or 2 <input type="checkbox"/> 3 to 5 <input type="checkbox"/> 6 to 9 <input type="checkbox"/> 10 or more <input type="checkbox"/> Unknown
11. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide? <input type="checkbox"/> None <input type="checkbox"/> 1 or 2 <input type="checkbox"/> 3 to 5 <input type="checkbox"/> 6 to 9 <input type="checkbox"/> 10 or more <input type="checkbox"/> Unknown

Section G: Please indicate how satisfied you are with the degree to which your family engages in the following behaviors.

How satisfied am I that....	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. My family enjoys spending time together.					
2. My family members help the children learn to be independent.					
3. My family has the support we					

need to relieve stress.					
4. My family members have friends or others who provide support.					
5. My family members help the children with schoolwork and activities.					
6. My family members have transportation to get to the places they need to be.					
7. My family members talk openly with each other.					
8. My family members teach the children how to get along with others.					
9. My family members have some time to pursue our own interests.					
10. Our family solves problems together.					
11. My family members support each other to accomplish goals.					

12. My family members show that they love and care for each other.					
13. My family has outside help available to us to take care of special needs of all family members.					
14. Adults in our family teach the children to make good decisions.					
15. My family gets medical care when needed.					
16. My family has a way to take care of our expenses.					
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).					
18. My family is able to handle life's ups and downs.					
19. Adults in my family have time to take care of the individual needs of every child.					
20. My family gets dental care when needed.					

21. My family feels safe at home, work, school, and in our neighborhood.					
22. My family member with a disability has support to accomplish goals at school or at a workplace.					
23. My family member with a disability has support to accomplish goals at home.					
24. My family member with a disability has support to make friends.					
25. My family has good relationships with service providers who provide services and support to our family member with a disability.					

Section H: Provide simple directions. Please read the following statements and indicate how strongly you agree with the statement.

Statement	Strongly Agree (1)	Agree (2)	Slightly Agree (3)	Slightly Disagree (4)	Disagree (5)	Strongly Disagree (6)
1. The problems						

<p>of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.</p>						
<p>2. I have met my own personal expectations for expertise in caring for my child.</p>						
<p>3. I would make a fine model for a new parent to follow in order to learn what she would need to know to be a good parent.</p>						
<p>4. Being a parent is manageable, and any problems are easily solved.</p>						
<p>5. If</p>						

anyone can find the answer to what is troubling my child, I am the one.						
6. A difficult problem about being a parent is not knowing whether you're doing a good job or a bad job.						
7. Considering how long I have been a parent, I feel thoroughly familiar with the role.						
8. I honestly believe I have all the skills necessary to be a good parent to my child.						
9. Even though						

<p>being a parent could be rewarding, I am frustrated now while my child is at his/her present age.</p>						
<p>10. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated.</p>						
<p>11. My mother was better prepared to be a good mother than I am.</p>						
<p>12. Sometimes I feel like I'm not getting anything done.</p>						
<p>13. I go to bed the same way I</p>						

wake up- feeling that I have not accomplish ed a whole lot during the day.						
14. My talents and interests are in other areas not in being a parent.						
15. If being a parent of an infant were only more interesting, I would be motivated to do a better job as a parent.						
16. Being a parent makes me tense and anxious.						
17. Being a good parent is a reward in itself.						

Section I (POST ONLY):

How many cruises have you been on with Autism on the Seas?

- 1
- 2-3
- 4-7

More than 7

Please document the months and years of your past cruises with Autism on the Seas.

Please check off the activities that you or your child participated in with Autism on the Seas.
Please write in N/A if the activity was not applicable to your particular cruise.

Priority Check in at the Port	
Lunch with Staff (*at least 2 times)	
Muster Drill	
Sail Away Party	
Dinner with Staff (*at least 2 times)	
Introductory Sessions	
Reserved Seating for Shows (*at least 2 times)	
Breakfast with Staff (*at least 2 times)	
Pool time with Staff	
Respite with Staff	
Group Party	
Aqua Show with Staff	
Beach Excursion with Staff	
Dad's Night out	
Mom's Night out	
Dinner Respite	
Dreamworks Breakfast	
Ice Show with Staff	
Family Portraits	

Lunch at Johnny Rockets with Staff	
Parent Meetup	
Royal Promenade Parade with Staff	
Private Shore Excursion Meeting	
Bowling Sessions with Staff	
Bumper Car Sessions with Staff	
Bungee Trampoline with Staff	
Carousel Session with Staff	
Flowrider with Staff	
Ice Skating with Staff	
Inline Skating with Staff	
Northstar Session with Staff	
Pool Slide with Staff	
Ripcord iFly with Staff	
Rock Wall Session with Staff	
Ropes Course Session with Staff	
Zip line Session with Staff	

What impact has Autism on the Seas had on you and your child's lives?

Study 2: Appendix B:

Section A: Demographics Survey

1. Age:
2. Ethnicity:
3. Location:
4. Marital Status:
5. Income:
6. Highest level of education completed:
7. Number of Children:
8. Number of Children with Special Needs:
9. # adults and # children living in household? (i.e., are there others there to help support)
10. Relationship with individual with special needs:
11. Age of Child:
12. Formal diagnosis of Child:
13. Behavior classification:
14. Communication Classification:

Section B: Interview Protocol- Semi-Structured:

Interview Questions:

1. What is respite and who is it for?
2. Please describe the type of respite services you have utilized.
3. What standards/ requirements do you use to select respite services?
4. What were the most beneficial components of these services?

5. What are barriers of respite?
6. What is the bare-minimum for parents respite?
7. Please tell me about some positive experiences with respite.
8. Please tell me about some negative experiences with respite.
9. Is all respite equal?
10. What are the reasons why you would choose not to use a respite service?
 - a. Is it because you have concern over the welfare of your child or the caregiver at the service?
11. Please describe your dream respite.