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Initiating a Peer Support Program for Parents of Children With Autism Spectrum Disorder in Richland and Lexington Counties

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INITIATING A PEER SUPPORT PROGRAM FOR PARENTS OF CHILDREN WITH
AUTISM SPECTRUM DISORDER IN RICHLAND AND LEXINGTON COUNTIES

by

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DEDICATION

To my loving husband, Thomas. Thanks for walking with me on this journey and supporting me every step of the way. Thanks for being strong when I was weak, brave when I was fearful, joyous when I was sorrowful, and a ray of hope when I wanted to give up. But most of all, thanks for being my best friend. – Danielle

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ABSTRACT

Objective: To initiate a parenting support program for parents of children with Autism Spectrum Disorder (ASD) in Richland and Lexington Counties.

Background: Parents of children with ASD have increased stress and a poorer sense of well-being relative to parents of children with typical development. This parent population in Richland and Lexington Counties identified lack of support as a major stressor. The parenting support model initiated (e.g. Parent to Parent program) is an evidence-based intervention used to provide peer support to parents of children with ASD. The training of veteran parents is essential in the development and initiation of a Parent to Parent (P2P) program which was the focus of the DNP project.

Methods: Initial recruitment consisted of posting flyers through community agencies with access to parents of children with ASD. Initially, I planned to recruit prospective veteran parents, provide the veteran parent training, and evaluate parental interest and satisfaction by response to recruitment effort and post-training questionnaires. This method posed many challenges and barriers. Using the feedback from the initial method to address barriers of scheduling, time and childcare, I modified and adapted the recruitment method to a family-centered approach by partnering with a local clinical psychologist who specializes in providing services to children with ASD. I was able to engage the parents who had to be present for services being provided for their children at the center. I initiated a portion of the veteran parent training during a scheduled social

skills/parent training session and evaluated the perceived satisfaction of the training using a 5-ordinal point, Likert-type questionnaire.

Results: Twenty potential veteran parents attended and were introduced to the P2P program. They completed a portion of the veteran parent training and wellness promotion activities. The purpose of this was to introduce the program and gather interests in becoming veteran parents. All participants completed the questionnaire. The overall composite score was 4.19 with a standard deviation of 0.2192. The parent scores indicated a high level of satisfaction with the content and the delivery method.

Conclusion: Potential veteran parents are interested in participating in the veteran parent training and P2P program. They acknowledged a need for the P2P program, understood its values and benefits, and were satisfied with the veteran parent training. Due to unique challenges in this parent population, it may be best to coordinate with a health care professional who has an established parent clientele and employ the peer support program in conjunction with an ongoing program.

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CHAPTER 1

PROJECT DESCRIPTION

INTRODUCTION

Autism spectrum disorder (ASD) is a “pervasive developmental disorder that involves abnormal development and function of the brain” (University of California San Diego [UCSD], 2016); spectrum refers to the “wide range of symptoms, skills, and levels of impairment or disability” (National Institute of Mental Health [NIMH], 2016b). ASD affects more than 3 million people in the U.S. (Buescher, Cidav, Knapp, & Mandell, 2014) and is the fastest growing developmental disability in the U.S. (Centers for Disease Control and Prevention [CDC], 2015b). ASD occurs in all racial, ethnic, and socioeconomic groups and is more prevalent in males. Approximately 100 children are diagnosed with ASD every day and a third of individuals with ASD have a comorbid intellectual disability (Autism Speaks, 2017). The psychological well-being of parents of children with ASD is compromised by the constant and relentless stress, responsibilities, and demands to provide medical and disability-related care to their children (Lee, 2009).

Parents of children with ASD experience increased stressors and challenges compared to parents of children with typical development (Kuhaneck, Madonna, Novak, & Pearson, 2015; Lai, Goh, Oei, & Sung, 2015). Thus, it becomes imperative for mental health professionals to address this underlying vulnerability by implementing evidence-based interventions to restore parental health and well-being (Kuhaneck et al., 2015). Nurses are in a key position to address this need by implementing evidence-based parenting interventions in order to promote parental health and functioning, parental support, and effective coping when caring for a child with ASD.

1.1 Description of Clinical Problem

ASD. ASD is large and variable in terms of child symptoms and degree of developmental impairment (CDC, 2015b). The spectrum can range from non-verbal, self-harming behaviors to above average intelligence (NIMH, 2016b). It is important to monitor children from birth to age five for developmental milestones. Symptoms of ASD typically present between 12 and 18 months and children are typically diagnosed by age four (Bleicher, 2013; Smith, Segal, & Hutman, 2017). Signs and symptoms of ASD might include (CDC, 2016):

- Avoiding eye contact
- Delayed speech and language skills
- Repetition of words or phrases
- Obsessive thoughts or interests
- Hand flapping
- Becoming easily upset over minor changes

There is no single cause of ASD and is likely that several factors play a role in its development. These factors may include both a genetic and environmental component. Other risks include a family history of ASD, older age of parents, single gene disorders, family history of immune-associated conditions, epigenetic processes, and pregnancy complications (CDC, 2016). These children can have developmental delays, speech impairments, behavioral issues, obsessive interests, repetitive behaviors, and poor social skills (CDC, 2015b). Treatment for these children is multifaceted and involves numerous interventions such as applied behavior analysis (ABA) therapy, speech therapy,

occupational therapy, sensory integration therapy, counseling, medication management, dietary changes, and special education resources (CDC, 2015c). These chronic symptoms, behaviors, and interventions can increase stress on the parents, severely disrupt the caregiver role, and cause strain on relationships, finances, work, and family life (Benson & Karlof, 2009).

Parenting. Parenting a child with ASD presents multiple challenges (Sikora et al., 2013). Parents are tasked with seeking an assessment, ensuring appropriate diagnosis, initiating and implementing various therapies and interventions, managing multiple appointments for medical care and other services, addressing behavioral issues, and tending to educational and occupational needs (Jellett, Wood, Giallo, & Seymour, 2015). This is also accompanied by higher levels of depression, anxiety symptoms, and maladaptive coping (Lai et al, 2015).

The term parenting stress is used to conceptualize the stress experienced by parents of children with ASD (Abidin, 1995) and is defined as the experience of distress or discomfort that results from demands associated with the role of parenting (Deater-Deckard 1998). Parenting stress has been associated with poorer social support, ineffective coping mechanisms, depression, and behavior disturbances of the child (Zaidman-Zait et al., 2010). Maladaptive coping consists of parents being highly critical of themselves for the problems they are facing, venting negative emotions, avoiding dealing with the situation, disengaging from the “problem” child, using distraction to avoid thinking about the situation, and simply giving up trying to find resolutions to their problems (Lai et al., 2015). Increased stress, maladaptive coping, and poorer well-being of the parent may also lead to a decrease in family functioning (Jellett et al., 2015),

interfere with the child's progress and development, and interfere with the effectiveness of the child's interventions (Huang et al., 2013). Therefore, it is imperative to address the mental well-being of these parents and implement evidence-based interventions (Huang et al., 2014).

Background Literature. Hayes and Watson conducted a systematic review of the literature to summarize the variability of parenting stress of parents with ASD children compared to parents of typical development children. Their meta-analysis revealed that the severity of ASD symptoms displayed by the child, intelligence, social skills, and agreeableness correlated with the experience of parenting stress (Hayes & Watson, 2013). Challenging behaviors such as deficits in social skills and communication tended to increase parenting stress (Hayes & Watson, 2013). The researchers concluded that the stress experienced by parents of children with ASD was a significant experience and was just cause for acknowledgement, attention, and intervention (Hayes & Watson, 2013).

Another systematic review conducted earlier reported that parents of children with ASD experienced high levels of depression and stress associated with a decreased sense of well-being, impaired role and social function, and poor overall health (Singer, Ethridge, & Aldan 2007). Higher levels of depressive symptoms have been shown to interrupt the interactions between the mother and her child. Mothers of children with ASD have been shown to respond more slowly to their children, be more irritable, have a more negative stance and outlook, and be more likely to use harsher discipline (Singer et al., 2007). The researchers found the parenting stress and distress experienced by parents of children with ASD to be amendable to intervention and concluded that intervention

efforts should be designed to foster attitudes, skills, and resources that would reduce distress and promote resilience and positive outcomes (Singer et al., 2007). Research has shown that the most significant amount of stress experienced by parents stem from the following: (a) the chronicity of the child's condition and diagnosis; (b) disapproval of the child's behavior by society and family members; and (c) lack of professional support (Dabrowska & Pisula, 2010). These stressors contribute to an increased prevalence of parental depression, increased anxiety, and poor physical health or health-related issues. Parents are faced with daily challenges that include behavior disturbances, communication, social impairments, and completing activities of daily living (ADLs) such as bathing, toileting, morning/bed rituals, and special diets (Lee, 2009). Parents must constantly address and attend to their children's affairs such as medical needs, care needs, special education, specialized resources, and general protection (Lee, 2009). Also, they must be strategic and prepared to deal with the complexity of the situation such as making difficult decisions concerning the child's care and progression. Decisions include planning for their child's future, considering the potential of long term care needs, considering housing and placement needs, and establishing a financial plan (Lee, 2009). Parents sometimes face negative attitudes, poor acceptance, and ridicule from society and family (Lee, 2009).

1.2 Scope of Problem

Prevalence. Neurodevelopmental disorders are among the top five chronic medical conditions affecting children in the United States. The CDC established the Autism and Developmental Disabilities Monitoring (ADDMM) Network to monitor the prevalence of children with ASD and other disabilities living in the U.S. (CDC, 2015a).

The prevalence of ASD has continued to increase and affects 1 in 68 children (CDC, 2016). The number of children between the ages of 6-17 with ASD is estimated to fall between 500,000 and 1 million (CDC, 2016).

In South Carolina. The South Carolina counties of Richland, Berkeley, Charleston, Dorchester, Barnwell, Lexington, Aiken, Anderson, Oconee, Pickens, Greenville, and Spartanburg have high prevalence rates of ASD for Medicaid recipients ages 0-18 (Centers for Medicaid and Medicare services [CMS], 2014). In 2012, 1.2% of eight-year-old children in South Carolina were diagnosed with ASD. The total prevalence in South Carolina is 11.1 children per 1,000 (Sausser, 2014) with boys being 1 in 55 and girls being 1 in 286 (Sausser, 2014). The prevalence also differs amongst racial groups. Per 1,000 children, African Americans have a prevalence of 9.9, Caucasians have a prevalence of 10.2, and Hispanics have a prevalence of 7.0 (Sausser, 2014).

Significance. ASD cost the nation \$126 billion per year in 2012 and that figure increased to \$268 billion per year by 2015 (Leigh & Du, 2015). One study projects the costs to rise to \$461 billion by 2025 if the current prevalence remains the same (Leigh & Du, 2015). If the prevalence continues to increase as it has, the study projects costs to top \$1 trillion by 2025 (Leigh & Du, 2015).

In 2011, the total annual cost of children with ASD in the U.S. was estimated to fall between \$11.5 billion - \$60.9 billion dollars (CDC, 2017). These figures included both direct and indirect costs associated with the care of children with ASD. In 2003, the medical expenses for children with ASD were 4.1-6.2 times greater than an average child without the disorder (CDC, 2017). In 2005, the average costs of medical care for autistic

children with Medicaid were 6 times greater than the cost of children without the disorder (CDC, 2017). Also, intensive behavior therapies and interventions reportedly cost \$40,000 to \$60,000 annually for each child (CDC, 2017). This economic impact crosses over into education. It costs more than \$8,600 extra per year to educate a student with ASD because of the need for additional educational resources (Lavelle et al., 2014).

ASD treatment services and the medical conditions associated with ASD place a substantial financial burden on the parents, and the cost is continuously growing (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014). The care required for children with this diagnosis often makes it harder for mothers to work. They generally work seven hours less than other mothers per week and earn 56% less (CDC, 2016).

Treatment for ASD. Applied Behavioral Analysis (ABA) therapy is the gold standard treatment for ASD. Evidence shows that it addresses behavior problems, develops looking and listening skills, enhances conversing, and promotes independence (Fishbein & Minshawi, 2017). It has also been shown to enhance the lives of children with ASD and allow them to live productive lives (Fishbein & Minshawi, 2017). The average cost of ABA services in South Carolina is approximately \$40,000 - \$60,000 per year for each child (Rotholz, Kinsman, Lacy, & Charles, 2017). Most private insurances do not cover the entire expense and some don't cover the therapy at all. In South Carolina, Medicaid has just started covering ASD treatment services (South Carolina Department of Health and Human Services [SCDHHS], 2017). However, parents are still experiencing delays and difficulties enrolling their children in ABA therapy due to a lack of therapists and accessibility. This adds an additional stressor and burden to parents

when their children are unable to receive the best evidence-based treatment for their disability.

Personal Experience. I am the mother of a child with ASD. I detected that something was wrong by age one, but he was not diagnosed until the age of seven despite several out-of-pocket evaluations conducted by physicians and psychologists. His first-grade teacher first recognized the symptoms of ASD and asked the school to conduct a formal evaluation that led to his diagnosis. At age seven, he was already too old for early intervention and was placed on a waiting list for ABA therapy; we are still on this waiting list three years later. In South Carolina, there are 9,000 Medicaid-eligible children with ASD but not enough service providers to conduct Applied Behavior Therapy, which is the gold standard treatment for ASD. My son has three different insurances (including 2 private insurances and Medicaid) and we still cannot locate a service provider.

As a child, my son was excused from four different daycares due to his behavior and I was forced to resign from three different jobs to care for him. During his early school years, his teacher would call or email every day complaining about his behavior. I begged his pediatrician to help us but she was not comfortable prescribing psychiatric medications. We were unable to see a pediatric psychiatrist right away due to long wait lists, not accepting new patients, or simply not accepting any insurance. I was forced to drive two hours to Charleston, SC to receive help and proper care for my son.

I volunteer and work closely with other parents of children with ASD. We all have stories of frustration and helplessness. One couple moved to South Carolina from New York after losing their home trying to pay for services for their son with ASD. Another couple moved from Florida and took a \$20,000 pay cut so that their child could

attend the Autism Academy of South Carolina because Florida does not offer a similar program. Another couple divorced because their marriage could not handle the stress of raising a child with ASD. Lastly, a single mom struggles with her son with ASD who is aggressive and physically abusive to her. Our stories are real, our burdens are heavy, our pain is enormous, and our daily struggles are overwhelming.

Subpopulations. Social status, income, race, and family structure play a huge role in the identification of ASD and receiving treatment. Minorities in this country are at an increased risk of parenting stress due to the disparities that exist. Minority children are more likely to be misdiagnosed with a conduct disorder, misdiagnosed with ADHD, have a late entry into specialty care, and to experience delays in receiving ASD services (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Caucasian children are 2.6 times more likely to receive an ASD diagnosis on the first visit with a specialist (Mandell et al., 2007). African American children are 5.1 times more likely to be diagnosed with an adjustment disorder in lieu of ADHD and are diagnosed at a later age than Caucasian Americans (Mandell et al., 2007).

Analysis of Current Practices. Currently, interventions used to service families of children with ASD primarily focus on the children and addressing their needs but does little to address the mental well-being and needs of the parents (Dykens et al., 2014). Parents are taught how to manage the child's cognitive delays, language deficits, physical disabilities, social impairments, and behavior difficulties. These interventions include awareness and education about the child's condition, training in advocacy, promotion and encouragement to participate in various disability-related organizations, and respite care to provide temporary relief for the caregivers. However, the programs are not purposed to

support the mental health of the parents of children with ASD (Dykens et al., 2014). Although respite care is designed to temporarily relieve caregiver strain and pressure by providing breaks, it does not address coping strategies or mechanisms to help parents deal with the situation once they return (Dykens et al., 2014).

Current Practices in South Carolina. The South Carolina Department of Disabilities and Special Needs (SCDDSN) is a state agency that provides case management services to individuals with disabilities (including ASD) in Richland and Lexington Counties. They work with various organizations and agencies to tailor care specific to each individual based on their disability.

The Richland/Lexington Disabilities and Special Needs Board is a division of SCDDSN that provides services to Richland and Lexington Counties. Rena Prince is a service coordinator with this board and serves as one of five ASD service coordinators within the organization. Ms. Prince expresses increasingly growing concerns and a dire need for mental health services, referrals, and resources to help parents and caregivers who have autistic children and has reached out requesting help for themselves. Ms. Prince reports that these parents often complain of “being stressed out, frustrated, down, not sleeping well, tired, angry, anxious, feeling all alone, and overwhelmed” (Ms. Prince, personal communication, 2016). Furthermore, she reports some of the parents “being at their wits end” during routine home visits and check-in calls; however, in this geographic area, there are currently no resources and services designed specifically for this parent population. She also reports that families who lack support and resources verbalize feeling overwhelmed more often than families with support. She has even experienced

cases where the family relinquish their parental rights to the state because “they can’t handle it”. Allison Randel is a clinical psychologist at the Autism Academy of South Carolina in Columbia, SC who works closely with autistic children. There, she runs a neurodevelopmental clinic, performs comprehensive assessments and testing for ASD and ADHD, provides social skills training to treat the social deficits often presented in this population of children, and conducts a summer camp (Camp MATES) to strengthen the social skills of these children. She similarly reports having inadequate recommendations or referral sources for parents who reach out to her wanting and needing help (Allison Randel, personal communication, 2016).

On August 10, 2016 and August 12, 2016, I spoke individually with the parents and/guardians of children with ASD who were participating in Camp MATES. The parents were interviewed when either dropping or picking their children up from camp. Parents were asked: (a) if they experienced additional stress due to having a child with ASD and (b) what aspects about the situation they found the most stressful. All twenty-six of the parents reported experiencing increased stress that they associated with having a child with ASD. The parents reported the following stressors:

- “the child never grows up and become independent”
- “having to constantly explain things” to the child
- “always having to remind [the child] of something”
- “learning challenges in school”
- “nutrition and food aversions”
- “not focused or listening at home or school”
- “behavior issues”

- “aggression”
- “doesn’t follow directions”
- “talks constantly”
- “anger outbursts”
- “dealing with too many doctors”
- “getting the initial help”
- “slow and aggravating process for help”
- “dealing with school districts”

The parents reported the following feelings:

- “always a sense of stress”
- “being tired of [the child]”
- “can never relax”
- “can’t focus on the positivity”
- “feeling overwhelmed”
- “worried about [the child] standing out”
- “afraid [the child] is going to do weird stuff”
- “can’t enjoy life”
- “life belongs to the child”
- “no life of my own”
- “can’t work due to obligations of the child”

There are no mental health providers in the Midlands area specifically addressing the needs, concerns, stressors, and mental well-being of these parents/caregivers; the

majority of support and resources are centered on the children. RLDSN does provide respite which gives the parents a short break; however, it's temporary, time limited, and doesn't provide any coping mechanisms or equip the parents with long-term resources/guidance to help them improve their mental well-being and parenting stress. Respite is an important service to provide and it's needed but it doesn't enhance the parent's capability to cope with the situation.

1.3 Purpose of Project

According to DDSN case manager, the parents of children with ASD in Richland and Lexington Counties reported increased levels of stress and a poorer sense of well-being (Ms. Prince, personal communication, 2016). Furthermore, they identified lack of support as a major stressor contributing to increased levels of stress and poorer sense of well-being. For the purposes of my DNP project, I want to implement an evidence-based intervention to increase support among parents of children with ASD in Richland and Lexington Counties.

Parents are routinely seeking advice and support (Chewning & Montemurro, 2016) when caring for themselves and their children. Support groups for parents can provide a means for parents to cope with the situation, receive information, help combat stress, network with other parents, and build a community (Clifford & Minnes, 2013). Research suggests that social support interventions may serve as an effective means to provide efficient, cost-effective support to these parents (Clifford & Minnes, 2013; Holtslander, Kornder, Letourneau, Turner, & Paterson, 2012; Reinke & Solheim, 2015).

1.4 Social Support Framework

Defining Social Support. Social support is defined as the development of relationships or communication with other people (e.g., an established network of family, friends, those with common interests, group/religious affiliations, members of the community) that are available to provide psychological, emotional, physical, and/or financial help in a time of need, which serves to enhance the perception of personal control and improve coping (Marifran & Gibb Hall, 2011). Several studies have indicated the importance of social support and its benefits on physical and psychological health and overall well-being. Research has found positive social support to increase resilience to stress, decrease the development of stress-related disorders and depression, and reduce the occurrence of disease processes and mortality (Ozbay, Fitterling, Charney, & Southwick, 2008; Seeman, T., 2008). It has also been linked to better psychological adjustment, improved efficacy, and improved coping (Marifran & Gibb Hall, 2011).

Conceptual Framework. The conceptual framework of social support by Hans Veiel will be used to guide this project. Veiel's framework is systematic, concise, and comprehensive. It focuses on social relationships and the interactions of individuals instead of a whole network. This framework is based on three different dimensions (Veiel, 1985):

1. *Support type* – refers to type of support being provided such as crisis, emotional, cognitive, practical, informational, and social integration.
2. *Relational context* – refers to the relationship between the recipient of the support and the one providing the support.

3. *Assessment Focus* – refers to the assessment of social support. One can choose objective measures such as frequency or subjective measures such as quality.

Peer Support. Peer support is an example of social support. It is emotional and informational support provided by a social network of members who have experienced a particular stressor or life experience of the target population and is knowledgeable about the situation and its accompanying stress (Dennis, 2003). Peer relationships have been shown to decrease feelings of isolation, alienation, and loss of control (Dennis, 2003).

1.5 PICOT Question

A PICOT question is used to govern clinical inquiry in search for best practices, and will generate knowledge and evidence to guide clinical decisions and patient care (Fineout-Overholt, Melnyk, & Schultz, 2005). It is an acronym for the following:

(P) – patient population

(I) – intervention

(C) – comparison group

(O) – outcome

(T) – Time (optional)

The evidence-based practice clinical question that guides this project is the following: (P) among parents of children with ASD in Richland and Lexington Counties, is (I) an evidence-based peer support program compared to (C) no structured peer support mechanism feasible as evidenced by (O) parental interest and satisfaction? Interest is

measured by response to recruitment effort. Satisfaction is measured through a post-intervention questionnaire and qualitative analysis of participant comments.

1.6 Definitions

For the purposes of this paper and evidence-based project, the following frequently used terminology is defined for clarification and understanding.

Autism spectrum paper and my evidence-based project, the following frequently *disorder* is often abbreviated as ASD and its definition was explained in the introduction section of this paper.

Stress is defined as a “process that consists of stressors (i.e., challenging events), mediators (i.e., constructs that enable us to evaluate the nature of a threat and the emotional and behavioral responses elicited by that threat), and the stress-response (i.e., physical and emotional responses elicited by a stressor)” (Foody, James, & Leader, 2015).

Parenting stress is a term used to conceptualize the stress that’s experienced by parents of autistic children and it’s defined as a maladaptive, psychological reaction in response to the daily demands of parenting (Deater-Deckard, 1998).

Depression is a serious mood disorder that “causes severe symptoms that affect how you feel, think, and handle daily activities, such as sleeping, eating, or working” (NIMH, 2016c) and can be caused by “genetic, biological, environmental, and psychological factors” (NIMH, 2016c).

Anxiety is an “emotion characterized by feelings of tension, worried thoughts and physical changes like increased blood pressure” (Anxiety, n.d.); anxiety can “interfere

with daily activities such as job performance, school work, and relationships” (NIMH, 2016a).

Coping is “defined as how one deals with stressful situations” (Lee, 2009). She further states that “coping often mediates how well one can adjust during stressful situations (Lee, 2009). Fraser and Galinsky describes *interventions* as “purposely implemented change strategies” (2010) that can be simple or complex and “may be developed at the individual, family, group, organizational, community, and societal levels” (Fraser & Galinsky, 2010).

Mental health is defined as “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (World Health Organization, 2001).

Well-being includes “the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfillment and positive functioning” (CDC, 2013).

Life satisfaction “refers to a judgmental process, in which individuals assess the quality of their lives on the basis of their own unique set of criteria (Shin & Johnson, 1978)” (Pavot & Diener, 1993).

Clinician is a “a person qualified in the clinical practice of medicine, psychiatry, or psychology as distinguished from one specializing in laboratory or research techniques or in theory” (Clinician, n.d.)

Health care provider is “a doctor of medicine or osteopathy, podiatrist, dentist, chiropractor, clinical psychologist, optometrist, nurse practitioner, nurse-midwife, or a

clinical social worker who is authorized to practice by the State and performing within the scope of their practice as defined by State law, or a Christian Science practitioner” (University of California, Berkeley, 2016).

Health care professionals are those who “provide essential services that promote health, prevent diseases and deliver health care services to individuals, families and communities based on the primary health care approach” (World Health Organization, 2016).

LITERATURE REVIEW

1.7 Analysis of Evidence

Literature Review. A review of the literature was conducted using four different databases to include CINAHL Complete, Medline, PsychInfo, and Social Sciences. I used the following parameters to guide my search: full text articles, publication dates from 1997 – 2017, evidence-based practice, peer reviewed, and English language. The inclusion criteria were (a) the study must target parents of children with ASD, other disabilities, or a chronic medical condition; (b) the study must contain, discuss, or evaluate some type of peer support intervention for this parent population; (c) the study must provide an exemplary model to guide implementation and practice; (d) and the intervention must offer various options of delivery to meet diverse needs.

I searched using the Boolean phrase “peer support” and “parent of children with disabilities”. This search yielded fourteen results. Thirteen studies were rejected; nine studies included interventions that did not meet the inclusion criteria and four studies were not appropriate for my population. One study was appropriate and met all the inclusion criteria. This study referenced the parent to parent model.

A Google search of “parent to parent” yielded several results including the national website – Parent to Parent USA (P2P). This website provides evidence-based recommendations, practices, tools, and support for implementing a new program. The Google search also included links to various statewide P2P programs i.e. New York, New Jersey, Pennsylvania, Georgia, and Washington. It also included a link to a local P2P program in Boone, North Carolina.

The recommendations and practices endorsed by P2P USA is from research conducted by George Singer; this article was included in the evidence table (see Appendix A). I then conducted a search in the same databases using the Boolean phrase “Author Singer” and “parent to parent”. This search yielded 60 results and the articles were not relevant to the purposes of the search. I refined my search by changing the Boolean phrase to “Author Singer and “parent-to-parent”. This search yielded 2 results. One article did not meet the inclusion criteria. The other article met the inclusion criteria and was included in the evidence table.

P2P USA also utilizes recommendations and practices from research conducted by Betsy Santelli. I then conducted a search using the Boolean phrase “Author Santelli” and “parent to parent”. This search yielded 2 results; one article was a duplicate and the other did not meet inclusion criteria. I then conducted a Google search of “Betsy Santelli”. The first result was a P2P handbook authored by Santelli, Poyadue, and Young titled *The Parent to Parent Handbook: Connecting Families of Children with Special Needs*. The book was written by co-directors and researchers from the University of Kansas, Beach Center on Families and Disability. These researchers collaborated with Parent to Parent, conducted research, and helped shape program development by ensuring

that best practices were being used (Santelli, Poyadue, & Young, 2001). This book provides evidence-based guidelines and practices for initiating a P2P program. It also includes various resources, training materials, documents, and forms to utilize in a P2P program.

Summary of Findings. The literature revealed that the P2P model is an evidence-based intervention used to provide peer support to parents of children with disabilities – including ASD. This peer intervention has evidence to support its use and effectiveness with this parent population, has shown to increase support compared to control groups, and has resources to guide implementation.

1.8 Parent to Parent

P2P USA is a national non-profit organization whose mission is to promote parent access to other parents for support in caring for children or adolescents with a special developmental need, mental health condition, or disability (<http://www.p2pusa.org>). This program connects parents of a newly diagnosed child or parents newly referred to the program with a trained “veteran” or “supporting” parent (Santelli, Turnbull, Marquis, & Lerner, 1995). The veteran parent is someone who has a child with a disability and therefore has the experience of someone who has “been there” (Santelli et al., 1995). This program is set apart from other programs because it provides the referred parents with the opportunity to work closely with parents who can provide emotional and informational support, and be receptive, responsive, flexible, and accepting (Santelli et al., 1995). This type of support cannot be provided by a clinician, health care professional, or any other source (Santelli et al.2000).

Research has found P2P programs to be an effective means of peer to peer support with over 80% rating the program as helpful (Santelli et al., 2000). The data suggests a direct relationship with the number of encounters the referred parent has with the veteran parent and the level of satisfaction experienced by the referred parent (Santelli et al., 2000).

P2P in South Carolina. South Carolina currently has a statewide P2P program through Family Connections, but several gaps have been identified that limit its ability to meet the parenting needs of families of children with ASD.

Gaps in Service.

- The existing P2P program caters to all forms of disabilities and is not specific to parents of children with a diagnosis of ASD.
- All ASD-focused course offerings for parents are held in Spartanburg, South Carolina, which is approximately a 3-hour round trip from Columbia. This is not convenient for families in Richland and Lexington Counties and may not be feasible for some families in other nearby SC regions due to lack of transportation, work schedules, childcare, and cost of gas. Limited recorded trainings are available online.
- A 4-hour, face-to-face veteran parent training is held monthly at different venues across the state; therefore, if a parent in Richland or Lexington Counties wanted to participate and train as a veteran parent, they would have to travel or potentially wait several months before the training is offered locally.

- The facilitator of the veteran parent training is not a clinician or healthcare professional and is therefore limited in providing specialized training, information, and services.
- The program’s advisory board includes several financial advisors, an attorney, lobbyists, a pediatrician, and two nurse specialists in obstetrics and women’s health. This lack of mental health professional representation might affect the board’s ability to make decisions around specialized mental health issues, patient advocacy, or other decisions that require the expertise of a mental health professional.
- Finally, the program offers no mental health resources, services, or referrals. Families are charged with seeking this information s from other sources with some parents simply not finding it at all.

1.9 Initiating a P2P Program

My overall goal is to develop a P2P Program specifically for parents of children with ASD in Richland and Lexington Counties. However, it is more feasible to implement this program in incremental stages, beginning with the implementation of a veteran parent training.

P2P Best Practices. There is not one specific model of a P2P program. There is also no contraindication for states to have more than one P2P program facilitated through different organizations. For example, Washington state has a statewide P2P program that is provided through The Arc of Washington State. In addition, they have several P2P programs provided through other sponsoring agencies.

P2P Program Recommendations. P2P USA has provided and endorsed evidence-based practices to utilize when developing and implementing a new program (Singer et al.1999). Recommendations are outlined below.

1. Begin with a smaller number of veteran parents and then gradually increase recruitment.
2. Recruit veteran parents by sharing the information and flyers with a partnering agency to include in their newsletter, Facebook page, website, etc.
 - a. Provide a means for prospective veteran parents to contact you or request more information.
3. Attempt to recruit veteran parents who represent diversity in background, family structure, and socio-economic status. Consider eliciting demographic information on the initial application.
4. Speak with prospective veteran parents individually to assess appropriateness for the role of veteran parent. Screening criteria should include:
 - a. Displaying comfort when discussing their personal adjustments to the diagnosis and family situation
 - b. Stating ability and comfort in providing initial contact and supporting others
 - c. Keeping one's composure when discussing referred parents' concerns
 - d. Respecting other people's values and beliefs.

- e. Communicating effectively
 - f. Displaying a level of maturity, compassion, and empathy
 - g. Availability
5. Provide a training program for the veteran parents. Trainings typically involve 8-12 participants and last 1 or 2 full-day sessions. Consider offering refreshments, using a community resource person as a speaker, and awarding certificates of completion. There is no specified format for the training, but P2P USA recommends the inclusion of content covering:
- a. P2P Program orientation
 - b. Information about the matching and referral process, follow-up procedures, crisis interventions, and confidentiality
 - c. Communication and listening skills
 - d. Self-reflection and awareness
 - e. Sharing personal experiences about ways the diagnosis has affected the family
 - f. Simulations and role playing to demonstrate appropriate interaction between the veteran and referred parent
 - g. Process of adjusting and adapting following the diagnosis
 - h. Cultural diversity
 - i. Community resources
 - j. Thinking positively
6. Provide a manual for the veteran parents to include handouts and material from the training.

7. Participants should be expected to make the initial contact with referred parents within 24 hours of being matched. They should also make at least four contacts within the first eight weeks of the match. The program coordinator should contact both the veteran parent and the referred parent after the match to ensure everyone is satisfied and to address any questions or concerns.
8. Provide on-going training/booster sessions for veteran parents.

Feasibility. I used a model by Melnyk and Fineout-Overholt (2015) to determine the feasibility of implementing a P2P program. Their model asks the following questions (Melnyk & Fineout-Overholt, 2015):

- Can the project be conducted in a reasonable amount of time?
- Is there an adequate number of potential participants to recruit into the project?
- Does the feasibility model suggests identifying who the potential community stakeholders will be?
- Have the settings for recruitment been identified and is accessibility a concern?
- Does the lead person (PI) have sufficient time and expertise to spearhead the effort?
- Are there major ethical or legal constraints to undertaking this project?
- Are there adequate resources available at the institution or clinical site to conduct the project? If the answer is no, what is the potential for obtaining funding?

These answers and explanations are addressed below:

- Program development can be a complex and tedious process; this is no different with implementing a new P2P program. At this time, it is not reasonable to develop and implement this entire program within my given time frame; therefore, my P2P program will be implemented in incremental stages.
- Partnering with a local nonprofit organization that provides services and case management to individuals with ASD can aid in recruitment and population accessibility.
- The lead person has sufficient expertise to spearhead this project. I am a healthcare clinician in the psychiatric field, nursing clinical instructor, and is the parent of a child with ASD.
- There are no ethical or legal constraints to implementing this project.
- Once again, partnering with a local agency or institution that routinely sees families with disabilities can help enhance the project by providing a network, additional resources, expertise, and site location.
- The initiation of this project requires little to no funding; however, I would like to provide the participants with light refreshments, lunch, and a small token of compensation for their time and inconvenience in participating in the training.

METHODS

1.10 Project Design

The training of veteran parents is essential in the development and initiation of a P2P program (Santelli et al.2001). Initially, I wanted to recruit prospective veteran parents, provide the initial training, and evaluate participant satisfaction with the training by means of a questionnaire. I partnered with Arc of the Midlands, a local community organization that advocates for individuals with disabilities and provide numerous services to address their specific needs and challenges, to recruit participants and host the veteran parent training. They distributed my recruitment flyer electronically within their network and posted it on their Facebook page. I also contacted parents who previously expressed a need for additional support and the case managers who requested support resources for their clients. I discussed the P2P program and its benefits with them and invited them to participate in the veteran parent training.

No one registered or participated in the training. I contacted parents who expressed interest in the training, case managers, and Arc of Midlands staff to inquire about the low recruitment response. I received feedback from these sources that identified several challenges and barriers in this parent population that were not considered in the development of the training, P2P program, or recruitment strategy. I used the feedback to adapt and restructure the project design and recruitment strategy. Please reference the “Discussion” section for more details.

Methods.

Current Design and Recruitment. I will partner with a Dr. Randel, clinical psychologist with the South Carolina Autism Academy. She runs a social skills group for

children with ASD. Each cohort meets one hour on Mondays for 10 consecutive weeks. Parents have the option of registering for the 4:30 pm or 5:30 pm group. Dr. Randel is now implementing a parent training program in conjunction with the social skills group where she invites community partners to share resources with the parents within that hour the children are receiving services. Due to the time constraints, I will only present a portion of the Veteran Parent Training to this parent population during both the 4:30 pm and 5:30 pm parent training. The purpose of this is to introduce the P2P program and veteran parent training, provide detailed information about the two, discuss the agenda and content of the full training, complete some of the training activities, gather interests in becoming veteran parents, and receive feedback that may warrant additional modifications to the training. I will also evaluate participant satisfaction with the content and delivery method by means of a questionnaire.

Inclusion criteria. Participants must (a) be parents, grandparents, guardians, foster parents, or primary caregivers of children with ASD; (b) live in Richland or Lexington Counties; (c) have access to a telephone; (d) have dependable transportation; (e) be able to read and write English; (f) be able to communicate verbally; (g) have access to the internet; and (h) have an active email account.

Parent Training Presentation. The training presentation will be delivered in-person. The resources consist of a training manual and PowerPoint presentation developed in conjunction with Tina Leonard, a Licensed Independent Social Worker who is employed with USC Law School (third member of my DNP committee). This manual is a combination of materials from existing P2P programs, previous social work trainings, wellness training activities found online, and items from The Parent to Parent Handbook:

Connecting Families of Children with Special Needs (Santelli et al., 2001). The participants will be asked to engage in discussions and various activities. The perceived satisfaction of the content and delivery method will be evaluated at the end of the session. The responses and feedback from this questionnaire will be used to make further adjustments and improvements to the parent training. It will also guide implementation of the P2P program. Researchers suggest that trained health professionals should deliver various aspects of the veteran parent training but should not be depended upon entirely because the program is parent directed (Santelli et al., 2001). I will facilitate the veteran parent training. I am a registered nurse with teaching and mental health nursing experience, who will be eligible for psychiatric nurse practitioner specialty certification pending completion of a doctoral degree in nursing practice in May 2018. Most significantly, I am the parent of an eleven-year-old child with ASD.

Outcomes. Likert-type questionnaires are often used to measure outcome assessments, particularly in educational research (Sullivan & Artino, 2013). They consist of 5- or 7-ordinal points in which participants rate the degree they agree or disagree with a given statement (Sullivan & Artino, 2013). I will administer a 5-ordinal point, Likert-type questionnaire to the participants after completion of the training to measure perceived training satisfaction. This questionnaire is found in Appendix B. It will consist of four different sections: (a) training videos, (b) content of training, (c) veteran parent role, and (d) overall satisfaction. There will also be a comment section.

When measuring less concrete, unobservable concepts such as satisfaction, confidence, and motivation, it is best practice to calculate a composite score(s) rather than analyzing the variables individually (Rickards, Magee, & Artino, 2012; Sullivan &

Artino, 2013); individual variables are less likely to capture the full scope and essence of the concept one is trying to measure (Rickards et al., 2012; Sullivan & Artino, 2013).

Next Steps. Participants are not obligated to become veteran parents or participate in the P2P program. For those who are interested in participating, I will use the evidence-based screening guide to determine appropriateness adapted from the model provided by Parent to Parent of Washington (see Screening Guide, Appendix C). I will then collect contact information to include name, address, phone number, and email address of the parents who meet the criteria (Appendix D). These individuals will be invited to participate in the launch of the P2P pilot program in Fall 2018.

1.11 Human Subjects

Human subjects will be recruited as volunteers to participate in a portion of the Veteran Parent Training. Risks of participating may include emotional vulnerability, being upset by others' experiences, and increased stress in sharing their situations. To minimize these risks:

- If any participants become disturbed or distraught during the training, they will be assessed by the trainer, who is a licensed registered nurse, to determine if they are able to continue. If they are not able to continue, they will be excused from the training. This risk is minimized as parents have verbalized a willingness and desire to share and talk about their experiences with other parents of children with ASD within a supported environment.
- Participants are at liberty to decline to participate in the training at any time and for any reason.
- Participants are not obligated to participate in the P2P program.

CHAPTER 2

SHORT REPORT MANUSCRIPT: “CHALLENGES AND CONSIDERATIONS WHEN IMPLEMENTING A SUPPORT PROGRAM FOR PARENTS OF CHILDREN WITH AUTISM”

¹ Simmons, D., Baliko, B., and Raynor, P. To be submitted to *Autism: The International Journal of Research and Practice*.

2.1 Abstract

This short report discusses challenges and lessons learned when initiating a peer support program for parents of children with autism. This parent population in a local metropolitan and rural area of South Carolina identified lack of support as a major stressor. The Parent to Parent (P2P) model is an evidence-based intervention used to provide peer support to parents of children with autism by increasing parent support. The training of veteran parents is essential in the development and initiation of a P2P program. I attempted to recruit prospective veteran parents by partnering with a local disability and case management organization to distribute flyers electronically and on social media. I planned to provide the veteran parent training and evaluate parental interest and satisfaction by response to recruitment effort and post-training questionnaire. No potential veteran parents registered or participated in the training; however, feedback elicited from parents and staff at the partnering organization suggested that barriers to parents' participation in the training were time, scheduling, child care, unfamiliarity with the concept and the trainer, and feeling emotionally unequipped to support others. Considering these findings, I am partnering with a clinical psychologist to implement the training using a family-centered approach to increase accessibility to services and resources for both the child and parent. It may be best to coordinate with a health care professional who has an established parent clientele and employ the intervention in conjunction with an ongoing program.

2.2 Introduction

Parents of children with ASD experience increased stressors and challenges compared to parents of children with typical development (Kuhaneck, Madonna, Novak,

& Pearson, 2015; Lai, Goh, Oei, & Sung, 2015). This higher level of stress oftentimes challenges their ability to cope. Thus, it becomes imperative for mental health professionals to address this underlying vulnerability by implementing evidence-based interventions to restore parental health and well-being, provide parental support, and promote effective coping for parents who are caring for a child with autism. (Kuhaneck et al., 2015).

2.3 Description of Clinical Problem

Parenting. Parenting a child with ASD presents multiple challenges. Parents are tasked with seeking an assessment, ensuring appropriate diagnosis, initiating and implementing various therapies and interventions, managing multiple appointments for medical care and other services, addressing behavioral issues, and tending to educational and occupational needs (Jellett et al., 2015). The chronic symptoms and behaviors of the child, balancing the schedule of multiple interventions, and engaging with an array of medical professionals can increase parenting stress and severely disrupt the caregiver role (Jellett et al., 2015). Also, parenting stress can cause strain on relationships, finances, work, and family life (Jellett et al., 2015).

Parenting stress refers to the experience of distress or discomfort that results from demands associated with the role of parenting (Abidin, 1995). Among parents of children with ASD, parenting stress has been associated with poorer social support, ineffective coping depression, and behavior disturbances of the child (Zaidman-Zait et al., 2010).

Examples of maladaptive coping include parents being highly critical of themselves for the problems they are facing, venting negative emotions, avoiding dealing with the situation, disengaging from the “problem” child, using distraction to avoid thinking about the situation, and simply giving up trying to find resolutions to their problems (Lai et al., 2015). Increased stress, maladaptive coping, and poorer well-being of the parent may lead to impaired family functioning (Jellett et al., 2015). It can also interfere with the child’s progress and development, as well as the effectiveness of the child’s interventions (Huang et al., 2013). Despite these challenges, parenting stress can be lessened through interventions designed to foster healthier attitudes, improve parenting skills, and promote utilization of resources (Singer et al., 2007). The goals of these interventions are to reduce distress, promote resilience, and produce positive outcomes.

2.4 Brief Overview of Current Practices

Interventions used to service families of children with autism primarily focus on the children and addressing their needs but do little to address the mental health and well-being of the parents. These interventions include awareness and education about the child’s condition and how to manage symptoms and behaviors, training in advocacy, promotion and encouragement to participate in various disability-related organizations, and assistance with respite care. Although respite care is designed to temporarily relieve caregiver strain and pressure by providing breaks, it does not address coping strategies or mechanisms to help parents deal with the situation once they return.

Locally, both parents of children with autism and the case managers working with them confirmed experiences of persistent stress and diminished well-being associated

with the demands of caregiving. Parents identified increased support as key personal needs.

2.5 Evidence-based Interventions

Research suggests that social support interventions may serve as an effective means to provide efficient, cost-effective support to this parent population (Clifford & Minnes, 2013). Several studies have cited its benefits on physical and psychological health and overall well-being (e.g., Clifford & Minnes, 2013; Marifran & Gibb Hall, 2011; Ozbay, Fitterling, Charney, & Southwick, 2008). Also, positive social support has been found to increase resilience to stress (Seeman, 2008). Support groups can provide a means for parents to cope with caregiving demands, receive information, help combat stress, network with other parents, and build a community (Clifford & Minnes, 2013).

Peer Support. Peer support is a form of social support that has been shown to decrease feelings of isolation, alienation, and loss of control (Dennis, 2003). It is emotional and informational support provided by a social network of members who have experienced a particular stressor or life experience of the target population and is knowledgeable about the situation and its accompanying stress (Dennis, 2003).

The Parent to Parent (P2P) model is an evidence-based structured intervention used to provide peer support to parents of children with disabilities, including autism. This program connects parents of a newly diagnosed child or parents newly referred to the program with a trained “veteran” parent (Santelli, Turnbull, Marquis, & Lerner, 2000). The veteran parent is someone who has a child with a disability and therefore has the experience of someone who has “been there” (Santelli et al., 2000). This unique type

of support cannot be provided by a clinician, health care professional, or any other source (Santelli et al., 2000).

2.6 Initial Methodology

In response to parents expressed need for support, I decided to initiate a local P2P peer support program for parents of children with autism to reduce parenting stress through increasing peer connections. The first step in the process is to recruit veteran parents to serve as peer support to parents in need of additional support. Parents who need additional support may include those with children who have been recently diagnosed with ASD or are undergoing a transitional period. It may also include parents who lack a support system or those who simply need more support. The training of veteran parents is essential in the development and initiation of a P2P program (Santelli et al., 2000). Initially, I wanted to recruit prospective veteran parents, provide the initial training, and evaluate participant satisfaction with the training by means of a Likert-type questionnaire. The training was to be delivered in two different formats – online and in-person. The online training consisted of accessing and watching P2P informational videos via YouTube two weeks prior to the second component. The in-person training was scheduled for five hours on a Saturday morning.

I partnered with a local community advocacy and service organization for individuals with disabilities to recruit participants and host the veteran parent training. They distributed my recruitment flyer electronically within their network and posted it on their Facebook page. I also contacted parents who previously expressed a need for additional support and the case managers who requested support resources for their clients. I discussed the P2P program and its benefits with them and invited them to

participate in the veteran parent training. All interested individuals were to contact me for registration. Recruitment lasted for six weeks.

Results. No one registered or participated in the training. I contacted the parents who previously expressed interest in the training, case managers, and community organization staff to elicit input about the low recruitment response. I received feedback from these sources that identified several challenges and barriers in this parent population that were not considered in the development of the training and P2P program or the recruitment strategy. Parents thought the P2P program and veteran parent training was an excellent idea and a beneficial program. Staff members even reported that parents frequently requested flyers and verbalized a strong interest in the training; however, they did not follow through. Barriers included unfamiliarity with the program and the trainer, concerns about meeting obligations, and feeling emotionally unprepared to support others. Logistical barriers included scheduling conflicts, time required for the training, and lack of child care. Additionally, some parents were unable to participate due to this year's record-breaking influenza season.

2.7 Discussion

Recruitment posed many challenges, obstacles, and barriers. The parents were interested in the P2P program and attending the training, but the challenges and conflicts superseded their interest.

Unfamiliarity. Some parents' unfamiliarity with the program and the trainer presented a barrier to training participation. Parents may have had a greater response to a program recommended or provided by a trusted health care professional. Also, more information and advertisement about the program in advance may be beneficial for those

concerned that demands of participation might be prohibitive. To address the barrier of unfamiliarity, I am adapting the recruitment method by partnering with a local clinical psychologist who works closely with autistic children and their families. She runs a neurodevelopmental clinic, conducts a summer camp to strengthen the social skills of children with autism, provides social skills training to treat the social deficits often present in this patient population, and provides parent training in conjunction with the social skills group. We will promote the program using flyers placed in strategic locations in the clinic and by notifying patients via email of its availability. In-person information sessions about the P2P program and veteran parent training will be offered. She will also refer parents of newly diagnosed children to the P2P program when appropriate.

Obligations and Emotional Challenges. Some parents felt emotionally inadequate to provide peer support to someone else. Others expressed concerns about adding another obligation to their encumbered schedules. To address these concerns, I adapted the P2P program and veteran parent training to incorporate more wellness promotion to increase resilience and manage stress. The wellness promotion activities include stress and time management tips, sleep hygiene, building happiness, and relaxation techniques. Also, I removed all obligations from the program. Parents are at liberty to participate in the training without ever being obligated to be matched with a parent in need of support. Parents can simply utilize the skills and information provided in the training for themselves.

Logistical Barriers. Logistical barriers prevented some parents from participating in the veteran parent training. Some parents did not want to attend a

Saturday training because it interfered with their limited personal time. Other parents could not accommodate a five-hour training held on any day; it simply was not conducive to their schedules. As the training did not offer child care, some parents could not attend due to lack of alternative child care. To address these barriers, I plan to merge the P2P program and veteran parent training with the clinical psychologist's social skills/parent training program. This new model uses a family-centered approach to increase accessibility to services and resources for both the child and parent. It also promotes parent participation.

The new model will allow parents to participate in peer support interventions while the children are receiving social skills training. The social skills cohorts run for 10 consecutive weeks in the Fall and Spring and meet for one hour each week. I will provide one hour of veteran parent training each week for the first 5 weeks of the program. Participants will receive a certificate of completion at the end of 5 weeks. This new format reduces the barriers of child care, weekend deterrents, schedule conflicts, and having multiple locations for services. It also prevents another service being added on parent's "to do" list.

Finally, several parents were not able to attend the training because either their children, spouse, household family member, or themselves were infected with the influenza virus. While there is no way to safeguard from illness, the veteran parent training will now be held September and April; these months are not included in the Influenza season. Once the P2P program is initiated, it will run continuously throughout the year.

2.8 Conclusion

In conclusion, parents of children with autism experience higher levels of stress and need additional support interventions to help combat that stress, promote resilience, and improve mental well-being. The P2P model is an evidence-based model used to provide peer support for this parent population; however, there are some considerations that should be taken into account when implementing this program and the veteran parent training. Time, scheduling, child care, unfamiliarity, and uncertainty about meeting obligations are deterrents for these parents. It may be best to coordinate with a health care professional who has an established parent clientele and employ the intervention in conjunction with an ongoing program. Implementing an evidence-based wellness intervention with this population to establish rapport and improve mental well-being before initiating a P2P program will ensure that parents' own needs are met before they are asked to extend their support to others.

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CHAPTER 3
FINDINGS AND CONCLUSIONS

3.1 Summary of Findings

I presented a portion of the modified Veteran Parent Training to both the 4:30 and 5:30 pm parent training groups. This portion consisted of an introduction to the P2P program and veteran parent training, detailed information about the two, benefits of the program, an outline and agenda of the full-length training, sharing family experiences, and completing a progressive muscle relaxation activity. The purpose served to introduce the program, gather interests in becoming veteran parents, and receive feedback that may warrant additional modifications to the veteran parent training. Also, the participants were given P2P manuals to browse through the content. I then evaluated the perceived satisfaction of the content and delivery method using a 5-ordinal point, Likert-type questionnaire. Twenty potential veteran parents attended the session, and all participants completed the questionnaire. The responses on the questionnaire ranged from strongly disagree to strongly agree with the corresponding values being 1 to 5 respectively. Data from the questionnaires was used to calculate composite scores in Microsoft Excel.

Quantitative Analysis

There were four sections on the questionnaire – training videos, content of training, veteran parent role, and overall satisfaction. The composite scores of each item is presented in Table 2. The composite scores and standard deviation of each section is provided in Table 3. Composite scores of individual items are rounded to the nearest tenth; however, the raw data was used to calculate the totals of each section. *Training Videos* received a score of 4.39 and a standard deviation of 0.2015. *Content of Training* received a score of 4.31 and a standard deviation of 0.2627. *Veteran Parent Role* received a score of 4.15 and a standard deviation of 0.3064. *Overall Satisfaction* received a score

of 3.90 and a standard deviation of 0.0943. The total composite score and standard deviation of the entire training presentation is provided in Table 4. The overall composite score was 4.19 with a standard deviation of 0.2192.

Table 3.1. Composite Scores of each Item

Training Videos	Composite Scores
The information in the YouTube videos (Chapters 1 and 2) was easy to understand.	4.6
I feel it's appropriate to have both an online and in-person component to the training.	4.5
The two-week notification prior to the in-person training is enough time to view the videos.	4.4
The length of the video series is approximately 45 minutes. I feel this length is appropriate.	4.2
The video study guide is needed to help enhance learning and identify important P2P concepts.	4.3
Total	4.38
Content of the Training	
The communication activities are appropriate.	4.3
The training in cultural diversity and awareness is beneficial.	4.3
Sharing family experiences is beneficial and appropriate in this training.	4.6
It is beneficial to role play veteran and referred parent interactions.	4.2
Discussing one's own adjustment process is helpful and appropriate for this training.	4.5

The wellness promotion activities and handouts are beneficial and useful.	4.5
I enjoyed the progressive muscle relaxation activity.	4.2
The training promotes participation and interaction.	4.0
Receiving a take-home manual is helpful.	4.5
Total	4.31
Veteran Parent Role	
I understand the role of the veteran parent.	4.4
This is a well-rounded training for the role.	4.0
Total	4.15
Satisfaction	
I am satisfied with this training.	3.9
I would recommend this training course to a potential veteran parent.	4
Total	3.90

Table 3.2. Composite Scores and Standard Deviation for each Section

Sections	Composite Score	Standard Deviation
Training Videos	4.39	0.2015
Content of Training	4.31	0.2627
Veteran Parent Role	4.15	0.3064
Satisfaction	3.90	0.0943

Table 3.3. Veteran Parent Introduction Composite Score and Standard Deviation

Veteran Parent Training	Composite Score	Standard Deviation
Total of all sections	4.19	0.2192

Qualitative Analysis

The evaluation questionnaire contained a comment section for participants to share their thoughts or opinions concerning the veteran parent training and P2P program. Overall, participants thought the training and P2P program was a great idea and found it beneficial. Some participants requested for the P2P program to include a component for the siblings of children with ASD.

3.2 Discussion

Initiating a P2P Program. My DNP project is a multidisciplinary approach to addressing the lack of support being reported by parents of children with ASD in Richland and Lexington Counties. The project involved the collaboration of nursing, social work, case management, psychology, non-profit organizations, and community partners.

Initial Project Design and Recruitment Method. No one registered or participated in the initial veteran parent training. I contacted parents who expressed interest in the training, case managers, and Arc of Midlands staff to inquire about the low recruitment response. I received feedback from these sources that identified several challenges and barriers in this parent population that were not considered in the development of the training and P2P program or the recruitment strategy. Parents thought the P2P program and veteran parent training was an excellent idea and a beneficial program. Staff members even reported that parents frequently requested flyers and verbalized a strong interest in the training; however, these barriers superseded the interest and prevented many parents from participating. Barriers included unfamiliarity with the program and the trainer, concerns about obligations, and feeling emotionally unprepared

to support others. Logistical barriers included scheduling conflicts, time required for the training, and lack of child care. Additionally, some parents were unable to participate due to this year's record-breaking Influenza season.

Unfamiliarity. Parents unfamiliarity with the program and the trainer presented a barrier to training participation. Parents may have responded more to a health care professional they were familiar with, had an established rapport, and trusted. Also, they may have responded more to a program recommended and endorsed by a trusted health care professional. In consideration of this barrier, an introduction, education, and advertisement about the P2P program in advance may be beneficial.

Obligations and Emotional Challenges. Some parents felt emotionally inadequate to provide peer support to someone else. These parents reported feeling “emotionally drained” and “not having anything to give”. Others expressed concerns about adding another obligation to their encumbered schedules already filled with various therapy appointments (e.g. physical therapy, occupational therapy, speech therapy, applied behavior analysis, social skills groups, etc.), health care provider visits, educational services, and behavioral concerns.

Logistical Barriers. Logistical barriers prevented some parents from participating in the veteran parent training. Some parents did not want to attend a Saturday training because it interfered with their personal time. Other parents could not accommodate a five-hour training held on any day; it simply was not conducive to their schedules. In addition, child care presented as another logistical barrier. The training did not offer child care; therefore, some parents could not attend due to lack of child care.

Illness. Finally, several parents were not able to attend the training due to illness. This unusual, record-breaking Influenza season affected many. Parents reported that either their children, spouse, household family member, or themselves were infected with the Influenza virus when the initial training was being held.

Modified Project Design and Recruitment. Considering the findings and feedback, I modified and adapted the recruitment strategy, veteran parent training, and P2P program to address these challenges and barriers and to accommodate this parent population.

Recruitment Strategy. I adapted the recruitment strategy by partnering with a well-known and trusted clinical psychologist, Dr. Randel, who has been working with families of children with ASD in Richland and Lexington Counties for several years. Through developing this partnership with a trusted provider, I was able to introduce and implement a portion of the veteran parent training during a scheduled social skills/ parent training session at Dr. Randel's clinic. This family-centered approach increased accessibility for both the child and parent by offering parent interventions while the children were receiving social skills training. It also promoted parent participation. This new format reduced the barriers of unfamiliarity, child care, weekend deterrents, schedule conflicts, and having multiple locations for services. It also prevented another service from being added on the parents' "to do" lists.

Illness. There is no strategy or method to safeguard from illness; however, this family-centered approach with a health care provider offered a benefit in monitoring and tracking participation. The front office staff enhanced communication between the clinic

and myself. They kept me updated on any scheduling changes for the parent and or child sessions.

Veteran Parent Training and P2P Program. I adapted the P2P program and veteran parent training to introduce the program purpose and focus more on wellness promotion activities aimed at increasing resilience and managing stress. The wellness promotion activities included stress and time management tips, sleep hygiene, building happiness, and relaxation techniques. Also, I removed all obligations from the veteran parent training and P2P program. Parents were at liberty to participate in the training without ever being obligated to be matched with a parent in need of support. Parents could simply utilize the skills and information provided in the training for themselves until they felt like they were ready to become a veteran parent in the future.

Questionnaire Responses. The *Training Videos* composite score of 4.39 indicates that participants agree with the statements concerning the appropriateness and comprehension of the information and content provided in the training videos. The *Content of Training* section received a composite score of 4.31. This suggests that participants agree with the content of the training, the activities being offered in the training, and its value in the learning experience and role development. The *Veteran Parent Role* section received a composite score of 4.15. This is slightly lower than the first two sections but still indicates a level of agreement among participants. Participants agree that they understood the role of the veteran parent after completing the training and that the training offered a well-rounded approach. The *Satisfaction* section received a composite score of 3.90 with a standard deviation of 0.0943; this standard deviation indicates minimal variability among responses. This score falls slightly below the

agreement category and into the upper end of the *neither agree or disagree* category.

Participants commented that this section was more difficult to score having only received a portion of the actual training. The overall composite score of the training was 4.19 and this indicates that participants were indeed satisfied with this training.

3.3 PICOT Question

My PICOT question was: (P) among parents of children with ASD in Richland and Lexington Counties, is (I) an evidence-based peer support program compared to (C) no structured peer support mechanism feasible as evidenced by (O) parental interest and satisfaction? Interest was measured by response to recruitment effort. Satisfaction was measured through a post-intervention questionnaire and qualitative analysis of participant comments.

The data, parental interest, feedback, and community support indicate that it is feasible to implement a P2P peer support program for parents of children with ASD in Richland and Lexington Counties. Participant's interest and attendance in the training increased once the recruitment strategy was adapted to address the challenges and barriers in the parent population. The quantitative and qualitative analysis suggests that participants acknowledged a need for the P2P program, understood its values and benefits, approved of the veteran parent training, and were satisfied with the training. I will use the feedback from the questionnaire and comments section to make additional adjustments to the training for future implementation.

3.4 Limitations

There were several limitations in this DNP project. The recruitment strategy had to be modified and adapted to account for specific parent challenges and barriers encountered during the initial recruitment design. This may have produced two limitations. First, the modification of the training did not allow for adequate advertising and notification prior to the presentation. Parents who took that particular social skills/parent training session “off” may have reconsidered if they were informed in advanced of this veteran parent training presentation. Second, due to time constraints, the modified recruitment design did not allow the entire veteran parent training to be presented. This may have caused some lower responses on the questionnaire concerning the content and overall satisfaction of the training.

Other limitations included partnering with a health care provider or single practice to implement a P2P program. This method had its benefits; however, it limited the reach of parents to only those affiliated with the practice. Also, this project design was limited to only English-speaking parents. This exclusion restricted parents who were non-English speaking from receiving this additional resource and support. Finally, the project design restricts parents without internet access and an email account from participating in the program. This may have limited parents in rural areas or of a lower socioeconomic status.

3.5 Conclusion

In conclusion, parents of children with ASD experience elevated levels of stress and need additional support interventions to help combat that stress, promote resilience, and improve mental well-being. The P2P model is an evidence-based model used to provide peer support for this parent population; however, there are some considerations

that should be taken into account when implementing this program and the veteran parent training. Time, scheduling, child care, unfamiliarity, and mental well-being are deterrents for these parents. It may be best to coordinate with a health care professional who has an established parent clientele and community trusts in order to establish and build provider relationships with parents. Also, it may be best to first implement an evidence-based wellness intervention with this population to establish rapport and improve mental well-being prior to initiating a P2P program.

3.6 Implications for Nursing Practice

Nursing is “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, facilitation of healing, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, groups, communities, and populations” (American Nurses Association, 2015). We have a broad scope of practice and the capabilities to care for all facets of one’s health. This includes caring for our patients beyond the four walls of a hospital or office.

Nurses are in a unique position to address the gaps in service for this parent population. We have the opportunity to promote population health by partnering with community leaders and organizations and by collaborating with parents and other health care professionals to provide a multidisciplinary approach to implementing community-based programs.

3.7 Future Evidence-based Projects

Dr. Randel and I will launch a P2P pilot program in Fall 2018 in conjunction with her social skills/parent training groups. This parent cohort will attend parent sessions

from September to early November. While the children are receiving social skills training, simultaneously, I will provide one hour of veteran parent training each week for the first 5 weeks of the program. Participants will receive a certificate of completion at this point. Participants can decide if they would like to be matched with a referred parent at this time. Parents are never obligated to be matched or participate in the P2P program. Some may simply want to utilize the skills personally and will have the option to do so.

Referrals. Dr. Randel runs a neurodevelopmental clinic and routinely conducts ASD screenings. She will discuss the P2P program with parents of children with newly diagnosed ASD. We will also place flyers advertising the program in designated locations in her office and send electronic copies to community partners and parents. Lastly, I will conduct informational sessions about the P2P and veteran parent training at the clinic.

3.8 Dissemination Activities

I plan to submit a short-report manuscript concerning this project to *Autism: The International Journal of Research and Practice*. It is a peer-reviewed, international journal that is published eight times a year. It focuses on research that enhances and improves the quality of life of those with ASD. This journal is multidisciplinary and has a broad focus that covers all aspects of this disorder. These areas include intervention, diagnosis, training, education, family issues, family services, and several other areas. The journal accepts research reports, review articles, short reports, and letters to the editors.

I plan to submit an abstract (see Appendix E) to display a poster exhibit at the 2018 South Carolina Nurses Association Annual Conference held in North Charleston, SC and the 2019 American Psychiatric Nurses Association (APNA) Conference held annually in Columbus, Ohio.

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APPENDIX A: EVIDENCE TABLE

Article #	Author(s) and Date	Evidence Type	Sample Size	Methods	Study Findings	Limitations	Evidence Rating	
							Level	Quality
1	Bray, L. Carter, B. Sanders, C. Blake, L. Keegan, K. 2017	Mixed method study: Qualitative interview data and quantitative questionnaire data Aim: to examine the influence of the parent-to-parent peer support scheme on parents' and their ability to deal with the day-to-day circumstances experienced when parenting a disabled child.	See methods' section	A prospective concurrent mixed method design with baseline and follow-up data collected to assess any changes occurring over the course of the scheme. Interview (n = 70) Questionnaire (n = 68) Data at two time-points from befrienders (n = 13) and befriendees (n = 26).	Parent to parent peer support acted as a catalyst for many parents to move towards a place where they could grow and begin to flourish and thrive. Professionals should inform parents who have a child with a disability that peer-to-peer parenting support schemes are a valuable and appropriate source of support and help.	Author did not address limitations in this article.	II	B

2	<p>Singer, G. Marquis, J. Powers, L. Blanchard, L. Divenere, N. Santelli, B. Ainbinder, J. Sharp, M. 1999</p>	<p>Mixed Design: Qualitative and quantitative study</p>	<p>128 parents in control group 56 in the treatment group</p>	<p>This study was conducted in five states: Kansas, New Hampshire, North Carolina, South Carolina, and Vermont.</p> <p>Quantitative study: based on a two groups (intervention and control) by two times (pretest and post-test) comparison design with random assignment.</p> <p>Qualitative study: conducted telephone interviews with parents using a standardized interview protocol. The interviewer was kept blind to the group status of the participating parents</p>	<p>Parent to Parent is a unique form of self-help for parents of children with disabilities.</p> <p>Suggest that parents who use Parent to Parent for non-emergency help benefit from contacts with other parents by (a) feeling better able to cope with their child and family situation, (b) feeling better able to view their family and personal circumstances in a more positive light, and (c) helping other parents make progress on goals that are important to them.</p> <p>Similarity of lived experience and social comparison was reported as important</p>	<p>All of the dependent measures relied upon self-report from parents.</p> <p>No third party or observational measures were used</p> <p>The study evaluated Parent to Parent over a fairly short time interval. It is possible that there are more powerful effects when measured over a longer period of time.</p>	II	A
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					aspects of the Parent to Parent experience.	The psychometric tool does not carry the same confidence of predictive and content validity that adheres to measures used and tested repeatedly.		
3	Santelli, B. Turnbull, A. Marquis, J. Lerner, E. 1995	Non-experimental Aim: report the results of a national survey of veteran and referred parents participating in parent to parent programs	240 referred parents 330 veteran parents 115 different parent to parent programs 43 states	Two questionnaires: one for the referred parents and the other for the veteran parents. Both surveys had closed and open ended items and opportunities to rank the importance of various items	Referrals are vital to the success of the program Veteran parent training is recognized as being important	Author did not address limitations in this article.	III	A

4	<p>Ainbinder, J. Blanchard, L. Singer, G. Sullivan, M. Powers, L. Marquis, J. Santelli, B.</p> <p>1998</p>	<p>Non-experimental</p> <p>Aim: to qualitatively examine the experiences of parents participating In Parent to Parent program</p>	<p>Twenty-four parents of children with special need</p>	<p>The parents participated in a semi-structured telephone interview. Qualitative analysis was performed</p>	<p>The self-help nature of Parent to Parent promotes highly efficacious relationships between referred and supporting parents.</p> <p>Improving the effectiveness of matches also has implications for training of supporting parents</p> <p>Parent to Parent can be used as a adjunct to existing support programs, or as a starting point for families new to disability.</p>	<p>Author did not address limitations in this article.</p>	III	B
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5	Santelli, B. Turnbull, A. Marquis, J. Lerner, E. 2000	Non-experimental Aim: reports on the descriptive results of a national survey of statewide parent-to-parent programs and suggests ways parent-to-parent programs can support and enhance their efforts.	n = 21 statewide parent to parent programs	2 surveys were mailed out parent to parent program coordinators across the nation.	Veteran parents offer credible emotional and informational support to new parents through the one-to-one parent match.	Author did not address limitations in this article.	III	A
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APPENDIX B: VETERAN PARENT TRAINING QUESTIONNAIRE

Title and Location of Training: _____

Trainer(s): _____

Date: _____

Instructions: Please indicate your level of agreement with the statements listed below by placing a check in the box.

1. Training Videos		Strongly Disagree (1)	Disagree (2)	Neither Agree or Disagree (3)	Agree (4)	Strongly Agree (5)
1.1	The information in the YouTube videos (Chapters 1 and 2) was easy to understand.					
1.2	I feel it's appropriate to have both an online and in-person component to the training.					
1.3	The two-week notification prior to the in-person training is enough time to view the videos.					
1.4	I would prefer to conduct all the training in-person instead of an online component.					
1.5	The length of the video series is approximately 45 minutes. I feel this length is appropriate.					
1.6	The video study guide is needed to help enhance learning and identify important P2P concepts.					
2. In-Person Training		Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
2.1	I would prefer to complete the entire training on one 5-hour day.					

2.2	Saturday is the best day to hold this training.					
2.3	I would prefer 1-hour trainings each week for 5 weeks in conjunction with the Linked Social Skills Program.					
Content of the Training						
2.4	The communication activities are appropriate.					
2.5	The training in cultural diversity and awareness is beneficial.					
2.6	Sharing family experiences is beneficial and appropriate in this training.					
2.7	It is beneficial to role play veteran and referred parent interactions.					
2.8	Discussing one's own adjustment process is helpful and appropriate for this training.					
2.9	The wellness promotion activities and handouts are beneficial and useful.					
2.10	I enjoyed the progressive muscle relaxation activity.					
2.11	The training promotes participation and interaction.					
2.12	Receiving a take-home manual is helpful.					
3. Veteran Parent Role		Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
3.1	I understand the role of the veteran parent.					
3.2	This is a well-rounded training for the role.					
4. Overall		Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
4.1	I am satisfied with this training.					

4.2	I would recommend this training course to a potential veteran parent.					
5. Comments						
5.1	What would you change about the training?					
5.2	How could we improve the training?					
5.3	Other comments or suggestions?					

APPENDIX C: SCREENING GUIDE

This list is an informal guide to screen and determine whether volunteers would make effective veteran parents. Keep these questions in mind as you are interviewing the volunteers, but do not ask parent these questions directly. Record your impressions of your conversation. The most important question is: What message would this potential veteran parent give to a referred parent?

Acceptance of the child:

- Do they view the child as a valuable person?
- Do they accept the child's strengths and weaknesses? Do they have reasonable expectations?
- Do they participate in services provided to their child?
- Do they advocate for change when necessary?
- Have they successfully worked through their feelings of having a child with a disability?

Ability to provide support to other parents:

- Are they willing to share their own experiences?
- Are they concerned about others? Are they nonjudgmental?
- Do they view the veteran parent role as a supporting role rather than a decision-making one?
- Are relationships within their family relatively stable?
- Are they coping well with emotional issues?
- Do they have an ability to identify the needs and feeling of others?

Ability to cope with other people's problems:

- Are they willing to become personally involved with other people?
- Can they cope with the problems of others without being hurt themselves?
- Can they handle confidential information without the need to discuss it with other people?

Ability to communicate:

- Do they express themselves well?

- Are they good listeners?
- Do they know when to be quiet?

Maturity:

- Can they work without a lot of praise or recognition?
- Are they willing to give to others without the expectation of returns?

Time:

- Do they have the time to be involved in this parent to parent program?

Final things to consider:

- Do they convey a sense of calm reassurance?
- Are they ready to share their knowledge and experiences effectively with another parent?

APPENDIX D: VETARN PARENT INFORMATION FORM

Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____ Phone #: _____

Email: _____

Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____ Phone #: _____

Email: _____

Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____ Phone #: _____

Email: _____

Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____ Phone #: _____

Email: _____

APPENDIX E: POSTER PRESENTATION ABSTRACT

Objective: To discuss challenges and lessons learned when initiating a peer support program for parents of children with autism.

Background: This parent population in a local metropolitan and rural area of South Carolina identified lack of support as a major stressor. The Parent to Parent (P2P) model is an evidence-based intervention used to provide peer support to parents of children with autism by increasing parent support. The training of veteran parents is essential in the development and initiation of a P2P program.

Methods: I attempted to recruit prospective veteran parents by partnering with a local disability and case management organization to distribute flyers electronically and on social media. I planned to provide the veteran parent training and evaluate parental interest and satisfaction by response to recruitment effort and post-training questionnaire.

Results: No potential veteran parents registered or participated in the training; however, feedback elicited from parents and staff at the partnering organization suggested that barriers to parents' participation in the training were time, scheduling, child care, unfamiliarity with the concept and the trainer, and feeling emotionally unequipped to support others. Considering these findings, I am partnering with a clinical psychologist to implement the veteran parent training using a family-centered approach to increase accessibility to services and resources for both the child and parent. Also, we will launch a P2P pilot program in Fall 2018 in conjunction with services offered at her clinical

practice. The veteran parent training and P2P program outcomes will be available in late fall of 2018.

Conclusion: In conclusion, it may be best to coordinate with a health care professional who has an established parent clientele and employ the intervention in conjunction with an ongoing program.