Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

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Primary caregivers of children with developmental disabilities (DD) are critical for supporting the development of the children for whom they provide care. In order to most effectively provide care, caregivers of children with DD need to be physically and psychologically healthy. However, caregivers of children with DD can experience challenges in these areas as a result of stress. Health-promoting self-care and social support can mediate the stress process to influence health outcomes. Given that a lack of social support is a barrier to engaging in health-promoting self-care, social support is needed for caregivers to engage in health-promoting self-care and together they are effective in mediating the stress process. However, caregivers of children with DD often experience barriers to receiving social support and engaging in health-promoting self-care and facilitating in-person supports for caregivers is not always feasible. Technology, specifically social media, has shown promise as a mode of intervention delivery. However, there are currently no published studies that have explored Facebook group interventions, which capitalize on social support, that target health-promoting self-care for caregivers of children with DD. The current study employed an exploratory sequential mixed methods design to develop and pilot a Facebook-delivered health-promoting self-care intervention for caregivers of children with DD.

*Keywords: Family Caregivers, Stress, Social Support, Health-Promoting Self-Care, Facebook*
Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

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A Dissertation
Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy at The University of Connecticut 2020
Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

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2020
Acknowledgements

I would not be writing this statement if it weren’t for my advisor and mentor, Dr. Sandra Chafouleas. Nearly six years ago, she responded to my email asking whether she had any opportunities for an undergraduate research assistant and throughout this time, she has provided me with countless opportunities to grow and learn, along with guidance, support, and encouragement. I am grateful every day that she responded to my email – the words “thank you” are not enough to express my gratitude. To Drs. Lisa Sanetti and Nicholas Gelbar, thank you for your belief in this work, for your support, and for helping to shape me into a better researcher and school psychologist. To Dr. Mary Beth Bruder, thank you for your time, thoughtful feedback, and encouragement to continue this work. Dr. Melissa Bray, thank you for always believing in me, and for your support throughout this process.

I would also like to thank Hannah Perry and Alyssa Bunyea for their assistance and support in completing this research – their work ethic inspired me to keep pushing through. In addition, I would not have made it through the last five years without the support and friendship of Taylor Koriakin.

To my parents, Hope and Bill Auerbach, and my sister, Mary, who have supported me from day one and who have always known I could do this, even when I didn’t believe it was possible. And, to my nephew, Andy, who is an endless source of joy and inspiration.

And finally, to my husband, John. Thank you for your unconditional love, patience, kindness, and support throughout this journey and process. Words cannot express how grateful I am today and every day to have you as my partner.
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Chapter I: Introduction

Statement of Purpose

The estimated prevalence of children aged 3 to 17 in the U.S. diagnosed with a developmental disability (DD) has increased substantially, with recent estimates around 7% of the total population (Zablotsky et al., 2017). The Centers for Disease Control and Prevention (CDC) define DDs as “a group of conditions due to an impairment in physical, learning, language, or behavior areas…[that] begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime,” (CDC, 2018). Of note, specific DD diagnoses (e.g., autism) have experienced increases over 200% in prevalence (Boyle et al., 2011). At the same time, the U.S. has moved toward the deinstitutionalization of individuals with intellectual and DD, with nearly all states having reduced their institutional populations by at least 50%, and with 18 states reducing this population by 90% or more over the last 50 years (Scott et al., 2008). This trend of deinstitutionalizing persons with DD has placed more care demands on the family, as an increased number of children with DD are living with their families (Carroll, 2013). There are approximately 16.8 million family caregivers of children with disabilities, age 18 and under, in the US; 55% of family caregivers are caring for their own children (National Alliance for Caregiving & AARP, 2009). Family caregivers, also referred to as informal or unpaid caregivers, are responsible for providing long-term in-home care for a child with DD (CDC, 2018). Typical care activities include support with dressing or undressing, grooming, medication needs, feeding, and toileting (Chafouleas et al., 2020; Family Caregiver Alliance, 2012).

Caregivers are instrumental for supporting the physical, cognitive, socio-emotional, behavioral, and academic development of children with DD (Pinquart, 2018). As a result, recent
national guidance has prioritized strategies to support the mental health of parents and caregivers as a means of improving mental, emotional, and behavioral outcomes for children and adolescents (National Academies of Sciences, Engineering, and Medicine, 2019). This further highlights research findings that caregivers of children with DD need to be both physically and psychologically healthy to facilitate the best possible outcomes for the children they support (Goudie et al., 2014; Quinn et al., 2013). However, maintaining health and well-being has shown to be challenging for caregivers of children with DD given the many stressors involved with caregiving (Carroll, 2013; Chafouleas et al., 2020). Although several barriers are often present, one that can be targeted through intervention is a lack of social support. As indicated by prior research, it is critical to facilitate social support for caregivers of children with DD because social support can serve as a protective factor against physical and psychological health problems that result from chronic stress (Brehaut et al., 2004; Cantwell et al., 2014; Dunn et al., 2001; Gallagher & Whiteley, 2012). Further, in order to combat existing physical and psychological health problems resulting from stress experienced by caregivers of children with DD, an intervention targeting health-promoting self-care is also needed. Thus, an intervention delivered through an online support group may simultaneously combat barriers to social support and health-promoting self-care among caregivers of children with DD.

Recent national recommendations have emphasized the importance of utilizing technology to expand social support networks as a means of improving health outcomes (DeHoff et al., 2016; Healthy People 2020, n.d.). Delivering interventions through an online social network removes several barriers (e.g., time constraints, childcare, transportation) by reducing or eliminating the need for in-person visits (Pagoto et al., 2016). Social media platforms can be adapted for different purposes, which makes them ideal for delivering interventions (Hamm et al., 2013). In
addition, use of general social media sites (e.g., Facebook, Twitter) has become part of many people’s daily routine, which can make it less burdensome for individuals to participate in an intervention delivered through these platforms (Laranjo et al., 2014).

Although the literature base on interactions within online communities is robust, much less research exists around interventions for health promotion (Syred et al., 2014). For example, recent studies have explored use of online support groups with caregivers (Niela-Vilen et al., 2014), but the evidence-base for using social media to promote health and facilitate social support among caregivers of children with DD is limited (Hamm et al., 2013). Specifically, no published studies to date have explored the effects of Facebook groups, which are free to join and participate in, on the health-promoting self-care of caregivers of children with DD. As such, the purpose of this study was to develop an intervention delivered through a Facebook group designed to facilitate social support and increase health-promoting self-care among caregivers of children with DD.

**Research Questions**

This study occurred in two phases. Phase One sought to explore the characteristics of caregivers of children with DD who participate in existing Facebook support groups and identify targets for a Facebook group intervention to increase health-promoting self-care and social support. The primary research questions for Phase One included:

1.) What are the characteristics of caregivers of children with DD who participate in existing Facebook support groups?

2.) What are the experiences and needs of caregivers who participate in Facebook support groups around stress, health-promoting self-care, and social support?
Building on information gleaned from Phase One, Phase Two included development and initial evaluation of a Facebook-delivered health-promoting self-care intervention for caregivers of children with DD. In addition, it was also necessary to determine whether Facebook is an effective modality for intervention delivery among this population. The primary research questions for Phase Two included:

1.) Do caregivers of children with DD who participate in the pilot intervention experience changes in (a) perceived stress, as measured by the Perceived Stress Scale (Cohen et al., 1983) and (b) health-promoting self-care, as measured by the Health-Promoting Lifestyle Profile, 2nd Edition (Walker et al., 1995)?

2.) How do caregivers of children with DD perceive the usability of a Facebook group as a mode of intervention delivery?

A third exploratory research question for Phase two included:

1.) Are there differences in weekly self-reported progress toward health-promoting self-care goals throughout the 8-week intervention?
Chapter II: Review of the Literature

Some aspects of caregiving can be rewarding, and many family caregivers experience positive health outcomes (Roth et al., 2015; Turnbull et al., 2015). However, family caregivers often experience increased risk for negative health outcomes (CDC, 2018; Robison et al., 2009). Caregivers have shown to experience greater stress than non-caregivers, which has been associated with increased risk for detrimental physical and psychological effects (Schulz & Sherwood, 2008). In fact, around 50% of family caregivers experience chronic physical (e.g., high blood pressure, obesity, high cholesterol) and psychological symptoms (e.g., distress, depression, anxiety, low subjective well-being) that have the potential to negatively impact their well-being and ability to effectively engage in caregiving activities (Chafouleas et al., 2020; Family Caregiver Alliance, 2012).

Across studies, both the perceived (obtained through self-report) and objective (e.g., stress hormones, use of medication, immune system functioning) physical health of family caregivers has shown to be poorer compared to non-caregivers (Pinquart & Sorenson, 2003; Pinquart & Sorenson, 2007; Vitaliano et al., 2003). Caregivers of adults with cancer have shown to experience chronic and significant symptoms of depression, anxiety, and psychological distress (Braun et al., 2007; Fridriksdottir et al., 2011; Lambert et al., 2013; Mosher et al., 2013; Mosher et al., 2015), which is particularly problematic as caregiver mental health has been associated with the physical and emotional well-being of persons with advanced cancer (Wadhwa et al., 2013). Although some of these findings may be generalizable to caregivers of children with DD, studies have demonstrated caring for a child with DD presents unique challenges that need to be considered.
**Stress Among Caregivers of Children with DD**

The challenges of caring for a child with DD have been fairly well-documented (Lindo et al., 2016). In addition to balancing traditional parenting roles with work demands, caregivers experience specific challenges associated with caring for a child with DD (Carroll, 2013). Specifically, under the Individuals with Disabilities Education Act (IDEA), children with disabilities between the ages of 3 and 21 are required to receive services in schools (IDEA, 2004). This presents caregivers of children with DD in this age range with the challenge of navigating through education laws, paperwork, and meetings with educational professionals in addition to frequent medical and other outside appointments (Carroll, 2013). In addition, finding appropriate afterschool care or childcare has shown to be difficult for these caregivers of children with DD (Anderson et al., 2018). Other noted challenges for caregivers include: marital strain, family interference, stress resulting from greater financial responsibilities, lower parental self-efficacy, physical burdens, challenging child behaviors, concerns about lifelong support for the child, and perceived social isolation (Baker-Ericzen et al., 2005; Freedman et al., 2012; Gammon & Rose, 1991; Hall & Graff, 2012; Iadarola et al., 2019; Karst & Van Hecke, 2012; Lindo et al., 2016; Parish et al., 2012).

As with caregivers of other populations, the previously mentioned challenges and others can lead to increased caregiver stress, which threaten a caregiver’s health and well-being and subsequently increase risk for physical and psychological conditions such as heart disease, cancer, gastrointestinal disorders, depression, and poor sleep patterns (Lindo et al., 2016; Pender et al., 2015; Trute & Hiebert-Murphy, 2002). Research shows that caregivers of children with DD experience physical and psychological distress at a higher rate than caregivers of children who are typically developing (Goudie et al., 2014; Pinquart, 2018). For example, several recent
studies have found caregivers of children with DD to report physical health challenges at a higher rate than non-caregivers (Cantwell et al., 2014; Gallagher & Whiteley, 2012; Lovell et al., 2012; Raina et al., 2005). Similarly, a recent meta-analysis found a negative association between caregiver health and each DD diagnosis among caregivers of young children with DD (Masefield et al., 2020). Specifically, caregivers of children with DD report experiencing high blood pressure, overweight and obesity, asthma, depression, and anxiety as a result of increased stress (Gallagher & Whiteley, 2012; Gallagher & Hannigan, 2015; Lach et al., 2009; Lushin & O’Brien, 2016). Given the number of issues associated with chronic stress among caregivers of children with DD, there is a critical need to identify contributing factors that can explain and inform directions for prevention, risk identification, and early remediation. In other words, understanding the relationship between caregiver stress and physical and psychological outcomes is critical for identifying points for prevention and intervention.

The Stress Process Model of Caregiving (SPMC; Pearlin, Mullan, Semple, & Skaff, 1990) provides a potential explanation of how coping behaviors and social support mediate the stress process to influence health outcomes and provides potential points for intervention. The SPMC highlights ways in which personal and psychosocial resources are connected, while also indicating the different impacts they can have on evaluations of stress outcomes (Dillahunt-Aspillaga et al., 2013). The three elements of the SPMC include stressors, mediators, and outcomes (Kim & Chung, 2014). Pearlin (2010) defined stressors as: “the broad array of problematic conditions and experiences that challenge the adaptive capacities of people,” (p. 208). Pearlin and Skaff (1996) identified three categories of stressors: eventful stressors (e.g., getting married, getting divorced, having children, losing a job, or the death of a loved one), chronic stressors (e.g., ambient threats to safety and security, caregiving, conflicts involving
family members), and quotidian stressors (e.g., any stressor experienced as part of fulfilling the requirements of daily life). Outcomes, or stress outcomes, are ultimately physical and psychological manifestations of stress (Pearlin et al., 1981). Mediators, or mediating resources, are behaviors, cognitions, and perceptions, such as coping and social support, that mediate the impact of stress-inducing conditions (Pearlin et al., 1981).

**Health-Promoting Self-Care**

Given the documented relationship between caregiving stress and physical and psychological health risks, it is critical for caregivers of children with DD to engage in health-promoting self-care, defined as “those actions persons take to improve their health, maintain optimal functioning, and increase general well-being,” (p. 73, Acton, 2002). Health-promoting self-care includes actions taken as a reaction to illness or symptoms of stress, but mostly refers to actions taken to prevent illness or maladaptive symptoms from occurring, such as healthy eating, getting enough sleep, and regular exercise (Acton, 2002). As defined in the SPMC, coping includes behaviors that that have any of the following functions: 1) modify situations that lead to stressful problems, 2) modify the meaning of stressful problems to reduce their threat, and 3) manage symptoms of stress (Pearlin et al., 1981). As such, health-promoting self-care, as defined, can be conceptualized as a coping behavior that mediates the stress process for caregivers of children with DD. Because interventions for caregivers of children with DD often employ a deficit-based approach (Carroll, 2013), a strengths-based or positive approach such as health-promoting self-care may likely be well-received. This is also consistent with a recent shift in research and practice toward using a strengths-based approach to understand outcomes for families of children with DD (Turnbull et al., 2015).
In a recent study, caregivers of children with DD were asked to rate their health-promoting self-care as compared to their ideal goal in six health-related areas: eat (i.e., consumption of appropriate nutrients and calories), sleep (i.e., sleeping at least seven hours per night), work (i.e., occupational satisfaction), play (i.e., time devoted to leisure and non-occupational activities), love (i.e., physical, psychological, and emotional intimacy and support), and learn (i.e., increasing knowledge for the purpose of personal growth; Chafouleas et al., 2020). Findings indicated that across participants, ‘eat’, ‘sleep’, and ‘play’ were the areas rated lowest, or farthest from their personal ideal goal (Chafouleas et al., 2020). In addition, other studies have shown caregivers of children with DD to report chronic sleep difficulties and headaches as negatively impacting their health (Cantwell et al., 2014; Gallagher et al., 2010; Hemmingsson et al., 2009; Morelius & Hemmingsson, 2013). When asked about the impact of caregiving on their overall health, over 50% of respondents in one study indicated chronic physical pain resulting from the physical challenges of caring for a child with DD (Murphy et al., 2006). Further, over 75% of these caregivers of children with DD also reported persistent feelings of anxiety, depression, guilt, and general emotional distress, with most desiring greater mental health support (Murphy et al., 2006).

Compared to non-caregivers, caregivers have shown to experience more barriers to health-promoting self-care and to engage in fewer self-care behaviors; however, those caregivers who engage in more self-care behaviors are shown to be better protected from the negative impact of stress on their well-being (Acton, 2002). For the many caregivers who do experience barriers to health-promoting self-care, time obligations involved in caring for a child with DD have shown to contribute to burden over and above financial and other obligations (McManus et al., 2011). However, the significant financial cost often involved in caring for a child with DD
can serve as a barrier to caregiver health care access; federal support and insurance may cover the child with DD, but caregivers are often required pay out-of-pocket for much of their child’s and their own health care (Caldwell, 2008; Carroll, 2013). Caregivers of children with DD have also identified low prioritization of their own well-being and difficulty obtaining respite hours from a qualified alternative caregiver as barriers to their health-promoting self-care (Carroll, 2013; Iadarola et al., 2019; Murphy et al., 2006). Further, the demands of caregiving have the potential to disrupt relationships with family and friends, to be physically stressful, and to negatively impact employment (Brannn & Heflinger, 2006; Seltzer & Heller, 1997; Resch et al., 2010). These barriers and others may contribute to the adverse psychological symptoms and distress experienced by many caregivers of children with DD (Resch et al., 2010). In order to effectively engage in prevention and intervention efforts to combat these barriers to engaging in health-promoting self-care, an additional mediator is needed.

**Social Support**

As defined in the SPMC, social support also mediates the stress process for caregivers. The broad construct of social support has been linked to myriad mental and physical health outcomes (Barrera, 1986; Cohen & Wills, 1985; Lakey & Orehek, 2011; Uchino, 2006, 2009). Many definitions of social support exist, but social support is generally thought of as “a person-environment interaction that decreases the occurrence of stressors, buffers the impact of stress, and decreases physiologic reactivity to stress,” (p. 198, Pender et al., 2015). Although the term ‘social support’ is often used interchangeably with ‘social network’ and/or ‘social integration,’ there are important differences in these three concepts (Pender et al., 2015). A social network is “the web of social relationships or social ties that surround an individual and the characteristics of those ties,” (p. 198, Pender et al., 2015). Social integration refers to “the degree of
involvement or participation in the social network,” (p. 199, Pender et al., 2015). Even though these terms overlap with the concept of social support, “Social support refers to resources within the network that are sensed as being available and helpful (perceived support) or are actually provided (received support),” (p. 199, Pender et al., 2015).

In particular, social support, particularly perceived support, may increase or reduce health behaviors depending upon social norms and a person’s social network (Cohen, 1988). Cohen (1988) suggested that: “the perception that others can and will provide necessary resources may redefine the potential for harm posed by a situation and/or bolster one’s perceived ability to cope…and hence may prevent a particular situation from being appraised as highly stressful,” (p. 278). Further, adequate support may prevent a negative response to stress by either reducing or stopping an emotional reaction, inhibiting biological processes, or preventing maladaptive behavioral responses (Cohen, 1988). For example, Trute and colleagues (2010) found that positive appraisals of social support were associated with lower levels of depression and perceived stress among caregivers of children with DD. In addition, in a recent systematic review, over half of studies exploring stress among families of children with severe DD found satisfaction with social support to correlate negatively with stress (Kyzar et al., 2012).

There is a substantial evidence base documenting the relationship between perceived social support and physical health outcomes (Uchino et al., 2012). Specifically, perceived social support has been associated with cardiovascular function (e.g., blood pressure, heart rate, coronary heart disease), endocrine function (e.g., levels of cortisol, epinephrine, norepinephrine), immune function (e.g., levels of immune cells, inflammation), and ultimately mortality, with lower levels of social support relating to poorer outcomes (Uchino, Cacioppo, & Kiecolt-Glaser, 1996; Uchino, 2006; Uchino et al., 2012). Health behaviors that have shown to be influenced by
social support include healthy eating, physical activity, smoking, and alcohol consumption (Cohen, 1988; Gallant, 2003). Further, social support has shown to have a positive impact on adherence to medical treatment and self-management behaviors across illnesses and diseases, age groups, and treatment regimens (DiMatteo, 2004; Gallant, 2003). As such, social support has been identified as a critical component of successful aging (Heinze et al., 2015; Schulz & Heckhausen, 1996).

Research has shown that since social support is inversely related to several psychological disorders and can protect caregivers of children with DD from the negative impacts of stress through altering their perception of a stressful situation, social support can influence caregivers’ physical health in a similar way (Cantwell et al., 2014). For caregivers to successfully engage in health-promoting self-care, they need support from family, friends, and/or peers (Pender et al., 2015). Among caregivers of children with DD, higher levels of social support have been found to predict psychological adjustment and resilience (Brehaut et al., 2004; Dunn et al., 2001; Gallagher & Whiteley, 2012; Iacob et al., 2020) and level of caregiver stress (Carroll, 2013; Kyzar et al., 2012; Plant & Sanders, 2007; Smith et al., 2001). For example, stress and social support have been shown to correlate, with caregivers of children with DD who report higher levels of social support also tending to report lower levels of stress (Bailey et al., 1994; Cantwell et al., 2014; Dunn et al., 2001). Among mothers of children with cerebral palsy, self-reported perceived stress and social support were shown to significantly predict well-being (Skok et al., 2006). Further, perceived social support was found to mediate the relationship between perceived stress and well-being (Skok et al., 2006). Social support has also shown to predict neuroendocrine functioning and increase cardiovascular health in caregivers of children with DD (Lovell et al., 2012). More recently, social support was found to be associated with blood
pressure and partially explained differences in systolic blood pressure between caregivers of children with DD and control parents (Gallagher & Whiteley, 2012).

As a result of the frequent isolation of caregivers of children with DD from the larger community, they often rely on others with similar circumstances for social support (Carroll, 2013). Caregivers of children with DD can benefit from receiving social support from others who care for a child with DD; the ability to share stories and experiences with one another can reduce a caregiver’s perceived isolation (Carroll, 2013). This type of social support can be referred to as peer support, which has been defined as “giving and receiving help and understanding another’s situation through shared experience,” (p. 1525, Niela-Vilen et al., 2014). Further, peer support is “social emotional support…which is voluntary, informal, flexible, non-hierarchical, and non-medical,” (p. 1525, Niela-Vilen et al., 2014). Peer support among caregivers of children with DD can provide necessary emotional support and information and resources; it may also help to increase positive perceptions of caregiving (Niela-Vilen et al., 2014; Turnbull et al., 2015). Benefits of peer support among caregivers of children with DD can include a shared identity or sense of community and learning practical information from one another (Shilling et al., 2013).

In addition to these benefits for individual caregivers, social support has been shown to relate to family quality of life (QOL; Singer et al., 2012). At the individual unit, QOL contains six domains: health, emotional well-being, social well-being, physical environment, and advocacy (Singer et al., 2012). Family-oriented QOL domains include parenting, family interaction, daily family life, and financial well-being (Singer et al., 2012). Within families, each individual’s QOL can impact both family QOL and individual family members’ QOL. As such,
the benefits of social support for caregivers has the potential to extend to the entire family and, ultimately, improve outcomes for children and adolescents with DD (Singer et al., 2012).

**Theory of Change: Extending Applications of the SPMC**

An adapted version of the SPMC that illustrates the relationship between stress, social support, and health-promoting self-care is available in Figure 1. Although in the original SPMC social support and coping (i.e., health-promoting self-care) are considered to be equivalent, given that a lack of social support is a barrier to engaging in health-promoting self-care among caregivers, the adapted model reflects that social support is needed for caregivers to engage in health-promoting self-care; together they are then effective in mediating the stress process. However, given the number of barriers to receiving social support and engaging in health-promoting self-care that caregivers of children with DD may experience, facilitating in-person supports for caregivers is not always feasible. Therefore, alternative methods for increasing access to interventions for caregivers of children with DD are needed. As a result, researchers have begun exploring the use of technology and social media to facilitate social support and promote health.

Over the last 20 years, the information technology revolution has altered how people interact, which presents greater opportunities and methods for receiving and providing social support (Pagoto & Bennett, 2013). One example of how technology can facilitate social interaction is internet support groups (Perkins & LaMartin, 2012). For individuals with health-related conditions, peer-to-peer internet support groups have shown to be an accessible source of support and guidance (Griffiths et al., 2015). Further, a recent study found that a peer-to-peer internet support group for depression was effective in reducing clinical symptoms of depression over a 6-month period when compared with a control group (Griffiths et al., 2012). Caregivers
have endorsed the positive effects of using the internet to obtain support and information
(Perkins & LaMartin, 2012). In a survey of family caregivers conducted by the National Alliance
for Caregiving (2011), 74% reported that using technology, even just use of the internet for email
and chat websites, could reduce their stress and increase their perceived caregiving effectiveness
(Perkins & LaMartin, 2012).

Interventions delivered through social media have the ability to combine user-generated
content with the power of social support to improve health (Syred et al., 2014). Typically, social
media has been found to promote higher levels of user engagement and retention compared to
other web-based interventions (Maher et al., 2014). Although the research base on using social
media to deliver health behavior change interventions is in its infancy, the vast majority of
studies included in a recent systematic review reported at least small positive effects (Maher et
al., 2014). There is a growing evidence base for the utility of Facebook support groups in
promoting positive health and social support outcomes.

Among adults with severe mental illness (e.g., major depression, bipolar disorder,
schizophrenia), a healthy lifestyle intervention delivered through a “secret” (i.e., only available
to and visible for invited members) Facebook support group was shown to be effective in
supporting participant weight loss (Naslund et al., 2018). Research has shown that internet-based
peer support groups can provide social and emotional support for mothers of children with
special health-care needs, with membership of an online social community serving an important
role in these groups (Niela-Vilen et al., 2014). For parents of children with autism, participating
in a Facebook support group was found to provide opportunities to share information and
resources about autism, parenting, and upcoming autism-related events (Cole et al., 2017;
Gerber, 2014). In addition, in a recent pilot study that sought to explore the health and well-being
of caregivers of children with DD, most participants expressed interest in a technology-based intervention to support their health-promoting self-care (Chafouleas et al., 2020). Further, over half of participants discussed using Facebook to receive social support from friends, family, and other caregivers (Chafouleas et al., 2020). In one study, a secret Facebook group, facilitated by a social worker, was created to promote peer support among bereaved family caregivers of hospice patients (Parker Oliver et al., 2015). Findings of this study indicated that participants found the Facebook group to be helpful, supportive, and largely easy to use (Parker Oliver et al., 2015).

**Purpose of the Present Study**

Although studies of Facebook interventions for other populations have shown promise, limited studies to date have explored the use of Facebook group to target the health-promoting self-care of caregivers of children with DD. As such, the goal of this study was to add to the literature by developing a Facebook-delivered intervention that capitalizes on social support to increase health-promoting self-care and subsequently reduce negative outcomes associated with stress. By evaluating these outcome measures, it was possible to explore whether changes in stress and health-promoting self-care would result based on participation in this intervention.
Chapter III: Phase One Methods and Results

Research Design

A mixed methods study was conducted to develop a Facebook group intervention for caregivers of children with DD. Mixed methods research (also referred to as multimethod, quantitative and qualitative methods, and mixed methodology) “involves the collection of both qualitative (open-ended) and quantitative (closed-ended) data in response to research questions or hypotheses,” (p. 217, Creswell, 2014). As this design draws on both qualitative and quantitative approaches, the limitations of both methods are reduced (Creswell, 2014). The current study employed an exploratory sequential mixed methods design, which begins with collecting qualitative data that can be used to inform the development of intervention content (Creswell & Plano Clark, 2018). Exploratory sequential designs generally occur in three phases, with qualitative data collection occurring in the first phase, development of an instrument or intervention in the second phase, and a quantitative evaluation of the instrument or intervention occurring in the third phase (Creswell & Plano Clark, 2018).

In the present study, data were collected in two distinct phases, with qualitative data collection occurring in the first phase and quantitative data collection occurring in the second. An integration phase occurred between phases one and two that involved using the qualitative results to build an intervention that is grounded in the culture and perspectives of participants and was then tested quantitatively. In Phase One, caregivers of children aged 3-21 were recruited to participate in a survey and subsequent focus groups to provide information on: a) the demographics of caregivers who participate in existing Facebook support groups and b) the needs and experiences of caregivers around stress, health-promoting self-care, and social support. Results from Phase One were used to determine the content and target(s) of the
intervention. In Phase Two, caregivers were recruited to participate in a pilot intervention designed to target areas of concern identified in Phase One. Phase Two employed a one-group pretest-posttest design, where participants completed the same measure prior to beginning the intervention and after completing the intervention. Although the one-group pretest-posttest design has frequently been criticized (Knapp, 2016), the design was chosen given its common use in intervention pilot and feasibility studies (e.g., Fitzsimons et al., 2013; Fowler et al., 2019; Patterson, 2016; Zuñiga et al., 2019).

**Phase One Methods**

**Recruitment**

In the spring and summer of 2018, a Google web search was conducted to identify a list of existing Facebook support groups for caregivers. The following search was conducted: site:www.facebook.com/“parents” OR “caregivers” AND “developmental disabilities” OR “autism” OR “ASD” OR “ADHD” OR “learning disability” OR “learning disorder” OR “intellectual disabilities” OR “cerebral palsy” OR “seizures” OR “deaf” OR “hearing loss” OR “blind” OR “stutter” OR “stammer”. In order for a Facebook group to be selected for use in recruitment, the group had to meet the following criteria: 1) classified as a Facebook group and not as a Facebook page; 2) include parents of at least one of the previously mentioned DD; 3) be written/conducted using the English language; 4) have a population of members primarily based in the U.S.; and 5) have at least 50 members. The search concluded when at least two Facebook groups were identified for each disability category.

The moderators of 39 Facebook support groups for caregivers were contacted to a) provide information about the study and b) request permission to recruit participants from their group. Of those contacted, 12 provided permission, five declined permission, and 22 did not respond after
at least two contact attempts. Upon receiving permission from the moderator(s), a graphic with information about the study was posted in the group along with a link to an online survey. Recruitment within each group occurred over a period of four weeks, with the recruitment post being posted one time per week. Participants who completed the survey and indicated interest in participating in a focus group were contacted to both confirm interest and obtain informed consent for participation. If a participant did not respond, they were contacted again once per week over a period of two weeks. After three failed contact attempts, participants were opted out of the study.

**Participants**

Caregivers of children with DD ($N = 82$) participated in the online demographic survey designed to provide information about the characteristics of caregivers who participate in existing Facebook support groups. Thirty-nine participated completed the survey in its entirety, and 32 partial responses were recorded. Nine respondents did not meet eligibility criteria, and two participants opted not to proceed beyond eligibility. Only complete survey responses were included in analyses. The majority of survey participants identified as female ($n = 38$). Tables 1 and 2 provide detailed demographic information on participants and the children for whom they provide care.

This survey was also used to recruit caregivers to participate in a focus group. From the pool of interested respondents ($N = 30$), 24 were invited to participate in a focus group because six participants did not provide contact information. Two participants responded to opt out of the study, 10 returned consent forms, and four attended a virtual focus group. All focus group participants were female, and their children ranged in age from 8 to 18 with diagnoses of attention deficit/hyperactivity disorder (ADHD; $n = 2$) and severe cerebral palsy (CP; $n = 2$).
**Inclusion Criteria.** In order to participate in the online survey, participants were required to be 18 years of age or older and a primary caregiver of a child aged from 3 and 21 who is diagnosed with at least one of the following DD: intellectual disability (ID); autism spectrum disorder (ASD); ADHD; CP; blindness; moderate to profound hearing loss; specific learning disability (SLD); seizures; developmental communication disorder (e.g., stuttering/stammering); or other developmental delay. The selected DD chosen to model from a study by the CDC and the Health Resources and Services Administration (HRSA) that examined the prevalence of DD in U.S. children from 1997-2008 (Boyle et al., 2011). Participants were also required to actively or passively participate in a Facebook support group for caregivers of children with DD at least two times per week based on participant self-report. For the purposes of this study, active participation was defined as creating original posts, posting a comment on their own post, or posting a comment on another person’s post. Passive participation was defined as “reacting to” another person’s post or viewing/reading posts in the group. Finally, participants were required to be proficient in reading and writing in the English language.

**Materials and Measures**

**Online Survey.** An online survey was administered using Qualtrics. As part of the survey, participants were asked to report demographic variables and indicate interest in participating in a focus group. A copy of the online survey is available in Appendix A.1. To confirm eligibility to participate in the study, participants were first asked whether they are the primary caregiver of a child with DD, their child’s age, and their child’s disability diagnosis. Those who did not meet inclusion criteria were exited from the survey and thanked for their interest in participating. Those who did meet inclusion criteria were asked to report their gender, age, race/ethnicity, marital status, education level, employment status, income, and relationship...
to the child they care for. Participants were also asked to report the following characteristics of the child they care for: gender, age at diagnosis, grade level, and educational support (i.e. Individualized Education Program [IEP] or 504 Plan). A selection of item content from the Caregiver Strain Questionnaire (Brannan et al., 1997) was adapted to explore some experiences around burden among caregivers of children with DD, and the scaling discussed on page 214 was used. Finally, open-ended questions were included about their current Facebook group. Specifically, participants were asked about the purpose of their Facebook group, what they perceive to be most helpful about participating in the group, and what might increase the benefits of participating in the group.

After completing the previous sections, participants were asked if they would be interested in participating in a focus group. Those who were not interested were exited from the survey and thanked for their time. Those who expressed interest were provided with an information sheet and asked to confirm their interest in the focus group. If participants no longer wished to participate after reading the information sheet, they were exited from the survey and thanked for their time. Those who were still interested were asked to provide their contact information, preferred form of contact, and the best time to contact them.

Focus Group Interview. A focus group interview “is a dynamic exchange of ideas based on questions and responses with a group of participants and researchers,” (p. 125, Trainor & Graue, 2013). To ensure that the focus group interview questions aligned with the research questions, a semi-structured interview protocol was developed (Appendix B). A semi-structured interview allows for the exchange of ideas based on open-ended questions developed by the researcher(s) and includes probes designed to elicit responses that will help participants to answer the questions (Trainor & Graue, 2013). The semi-structured interview included three
main questions designed to answer the second research question: 1) the experience of stress among caregivers; 2) current and ideal health-promoting self-care behavior; and 3) current support network and preferred types of social support. Each main question included two follow-up questions, with the semi-structured interview consisting of seven questions in total.

**Procedures**

**Focus Groups.** Once recruitment was complete, participants were contacted to confirm interest in participating in a focus group. The ideal number of participants per group depends on the type of research and purpose of the study (Trainor & Graue, 2013), but other intervention development studies have used between two and twelve participants in a focus group (Dennison et al., 2013; Hudson et al., 2002; Kay et al., 2016; Thomas et al., 2014; Washio et al., 2017). Participants were sent a link to an online scheduling poll, and focus groups were scheduled based on participant availability. The focus groups were conducted virtually using Cisco WebEx to remove geographic barriers to participation. All focus groups were recorded, and the audio was transcribed to aid in data analysis.

Two virtual focus groups were conducted between May and July 2019. The first focus group lasted 90 minutes. Five participants were scheduled to attend this focus group, but only one attended the entire focus group, with two participants joining for at least 30 minutes each. One of the two participants who did not attend sent a follow-up email indicating that they experienced some unexpected challenges with feeding and getting her child to bed, which is why they did not attend the group. The second virtual focus group lasted 32 minutes. Four participants were scheduled to attend this focus group, but only one attended. One of the three participants who did not attend sent a follow-up email indicating that their child was ill, which is why they did not attend the group.
Data Analysis. Data collected in Phase One was primarily analyzed using qualitative methods. However, data collected as part of the online survey was analyzed using descriptive statistics to determine the percentage of respondents that fell into each demographic criterion. Descriptive statistics were also used to analyze the caregiver burden items.

Participant responses to the open-ended survey questions and semi-structured focus group interview were analyzed using qualitative thematic analysis. In thematic analyses, qualitative data are reviewed to identify themes across a data set that can help to describe a phenomenon of interest (Braun & Clarke, 2012; Daly et al., 1997; Fereday & Muir-Cochrane, 2006). This review involves carefully reading through the data several times to search for themes or patterns that allow a researcher to conceptualize or uncover common experiences and meanings (Braun & Clarke, 2012; Fereday & Muir-Cochrane, 2006; Rice & Ezzy, 1999). In qualitative thematic analysis, the goal of analysis is to identify relevant themes or patterns that relate to or help formulate a research question (Braun & Clarke, 2012). There are two primary approaches to thematic analysis: an inductive approach in which the data are used to formulate codes and themes, and a deductive approach in which the researcher codes data using predetermined constructs or topics (Braun & Clarke, 2012).

Given that this was an exploratory study, an inductive approach was used in thematic analysis of the open-ended survey responses and focus group data. Braun and Clarke (2012) present a six-phase approach that was used to guide the inductive thematic analysis: 1) familiarize oneself with the data; 2) come up with initial codes; 3) identify themes or patterns; 4) review potential themes; 5) define and label themes; and 6) report the findings. First, the focus group transcripts were read carefully (e.g., highlighted, annotated) at least three times to ensure familiarity with the data. Second, the data were coded using descriptive or semantic labels to
identify features of the data that may be relevant to the research questions. Third, similar codes were grouped together to identify themes or patterns across the data. Fourth, potential themes were compared to the entire data set to verify that the themes are representative of the data and revise, combine, or eliminate themes that do not fit well. Fifth, the final set of themes were defined and renamed to clearly and succinctly summarize each theme. Finally, results of the inductive thematic analysis were synthesized into a report (i.e., the results section) that summarizes the findings.

Brantlinger et al. (2005)’s qualitative research credibility criteria were used to guide data collection and analysis. In other words, the student researcher, who conducted both focus groups, needed to consider the potential for her personal and professional characteristics, including prior assumptions, to impact her interactions with participants. The student researcher was a doctoral candidate in school psychology with a clinical background that could have shaped the content of discussions or participant openness. In addition, the student researcher was interested in research to develop an intervention for caregivers of children with DD; this might have affected data analysis and/or interpretation. To add other perspectives on participant responses and further increase the credibility of data analysis and interpretation, two graduate students studying school psychology who did not assist with data collection or initial analysis were recruited to review the focus group transcripts and the researcher’s conclusions. Finally, throughout the results section, the student researcher included a number of direct quotes from participants and a detailed description of findings to demonstrate evidence of how the findings were interpreted and subsequent conclusions were drawn based on guidance from Brantlinger et al. (2005).
Phase One Results

Survey Results

Child Characteristics. As shown in Table 1, a slight majority of children were male \( (n = 25) \). In addition, a majority of children were diagnosed with multiple disabilities \( (n = 24) \). Other disabilities included a diagnosis of developmental delay \( (n = 1) \), autism spectrum disorder \( (n = 4) \), attention deficit/hyperactivity disorder \( (n = 5) \), cerebral palsy \( (n = 2) \), a developmental communication disorder \( (n = 2) \), and a seizure disorder \( (n = 1) \). As shown in Table 2, across participants, their children ranged in age from 3 to 21 \( (M = 9.89, SD = 5.755) \) and the age at which their child received a diagnosis of a developmental disability ranged from birth to 15 years \( (M = 2.43, SD = 3.144) \). The majority of children regularly attend school \( (n = 36) \). Of those children who regularly attend school, the majority have an individualized education program \( (IEP; n = 32) \); four students have a 504 plan. The number of hours per day that children attend school varied but ranged from three hours per day to 10 or more hours per day.

Caregiver Burden. With regard to the caregiver burden items adapted from Brannan and colleagues (1997), participants rated their experience of burden as moderate. As indicated in Table 2, participants indicated that interruption of their time was most impacted as a result of caregiving \( (M = 4.03, SD = .986) \). Moderate difficulties were reported with regard to missing work or other responsibilities \( (M = 3.54, SD = 1.144) \), family routines being disrupted \( (M = 3.49, SD = 1.073) \), and challenges around social activities \( (M = 3.28, SD = 1.376) \). Moderate difficulties with feelings of isolation were also indicated \( (M = 3.31, SD = 1.379) \). Participants indicated fewer problems as a result of caregiving in terms of anyone in the family having to do without \( (M = 2.74, SD = 1.499) \), negative impacts on mental or physical health \( (M = 2.79, SD = \)
1.281), financial challenges for the family \((M = 2.62, SD = 1.444)\), and relationship challenges within the family \((M = 2.64, SD = 1.386)\).

**Facebook Group Participation.** Participants were asked to indicate the frequency of their active participation and passive participation in their current Facebook support group. As shown in Table 1, participants most frequently indicated that they actively participate in their Facebook group less than once per month \((n = 18)\). They most frequently indicated that they passively participate in their Facebook group between two and five times per week \((n = 13)\).

Participants were also asked to provide a description of the purpose of their current Facebook support group, describe what they perceive to be most helpful about participating in the group, and what would increase the benefits of participating in the group. With regard to the purpose of the Facebook group, two themes emerged in participant responses \((n = 38)\): emotional support \((n = 31)\) and information/resources \((n = 18)\). In terms of emotional support, one participant responded that the purpose of the group was “Support and understanding from other parents who understand what daily life with an STXer is like.” For information/resources, one participant indicated that the purpose of their Facebook group was a “Resource for families in our area for kids with ADHD.” Three themes emerged with regard to the benefits of participating in their Facebook group \((n = 38)\): a sense of support/community \((n = 25)\), information/resources \((n = 16)\), and the ability to share/vent without judgment \((n = 7)\). A participant who enjoyed a sense of support/community from their group responded: “Knowing there are others walking our walk.” One participant who found information/resources to be most beneficial indicated that the most helpful aspect was “People who have experienced the same issues that we are experiencing can recommend local resources to help.” In terms of the ability to share/vent without judgment, one participant wrote: “There is no one in my day to day life that understands what our life is
like. Signing on and being able to vent and give or receive encouragement during the tough times is priceless.”

Participant responses with regard to desired improvements to their Facebook support group (n = 27), six themes emerged: nothing or do not know (n = 12), greater connection with other parents (n = 6), in-person events/activities (n = 2), resource directory (n = 5), advice from professionals (n = 3), more specific to town/geographic area (n = 3). One participant who indicated a desire for greater connection with other parents and in-person activities wrote: “Group hangouts, vlogs, possibly regional meet ups. This would be great for our kids and for us as well.” Another participant who referenced wanting a resource directory responded: “Saved resources for a quick go-to list of doctors, activities for families.” In terms of advice from professionals, one participant shared that “Professionals helping to direct” would be beneficial. With regard to geographic region or town, a participant expressed a desire for “Localizing so resources could be shared in the same area where we live.”

**Focus Group Results**

A number of themes were identified within participant responses to each focus group interview question, and as such, results are presented within the questions asked in the semi-structured focus group interview: (1) sources and impact of stress; (2) current and ideal self-care behaviors; (3) current support network; (4) helpful and ideal types of social support.

**Sources and Impact of Stress.** Participants were asked to first describe the responsibilities or activities associated with caring for a child with DD that were the greatest source of stress. Three themes were present in participant responses: family/personal stressors (n = 4), professional stressors (n = 2), and social stressors (n = 2). Stressors that resulted from family or personal factors included the time commitments associated with caregiving activities
(e.g., attending numerous appointments, educational support, supporting activities of daily living, managing behavior), financial strain, role conflict (e.g., balancing multiple children or commitments), and concerns about the future. For example, one participant shared that “You feel like you’re always ‘on’…you know you have to work and then when you get home from work then you’re dealing with their projects…so there isn’t a lot of time to for yourself.” Professional stressors discussed by participants included a lack of understanding by professionals, the need to continuously relive or retell their child’s history, and activities involved in advocating for their child (e.g., dealing with insurance companies, schools, doctors). One participant stated that “You probably have already fought the insurance company, and the school, and you know whoever else you had to fight that day just to make your kid be accepted.” Some participants referenced social stressors, which included negative looks or judgment from others and comparisons they make when seeing other children who are healthy or typically developing. As one participant shared, “The stares I get and I’m like what is up with you people like I don’t get the stares, you know I mean like have you never seen a kid in a wheelchair?...When adults stare, why are you staring at my child?...Some days I don’t have the emotional capacity to deal with [it].”

Participants were then asked to describe how this stress impacts other areas of their life (e.g., work, relationships, leisure activities, diet, exercise, sleep). The primary theme that emerged was around the mental/emotional impact of stress ($n = 4$). Participants referenced feelings of frustration and guilt. For example, one participant shared that it is difficult “…if I’m working with [child] and it’s a hard day…managing own frustration.” Another participant noted: “I used to feel so guilty because I would get irritated or angry or whatever…at whatever happened and then I’m like…he can’t even help it.” Participants also referenced the impact of
stress on their physical health ($n = 2$), specifically with regard to exhaustion and a lack of sleep. One participant stated that “There’s not enough time in the day…I’m exhausted.”

**Current and Ideal Self-Care Behaviors.** Participants were asked to share their current self-care behaviors (e.g., going to the doctor/therapy/appointments, eating a healthy diet, getting 7-9 hours of sleep, regular exercise, going to place of worship/prayer, participating in Facebook or in-person support group). Four themes emerged with regard to current self-care behaviors: play/leisure activities ($n = 3$), social interaction ($n = 3$), physical health-promotion ($n = 2$), and working outside the home ($n = 2$). Play/leisure activities included going for a facial or massage, watching television, using Facebook, reading, and shopping. For example, one participant stated “…reading for me…when [child] is in bed if he’s happy and sleeping and quiet in bed, then I read.” With regard to social interaction, participants described sharing their story or providing support to others and connecting with other parents of kids with DD as self-care behaviors. One participant shared: “I just I like to post a picture and every time I post a picture of [child] I get tons of little hearts and smileys and hopefully it just brings them a little bit of hope you know.” Physical health-promotion activities included running and making time for sleep during periods of respite. For example, a participant indicated that “about 6 months ago I started…I used to run prior to having kids and about and then I didn’t for 12 years, and so I started running again in the morning with a group of people and so that’s been helping just like reduce stress.” Some participants also discussed working outside the home as a form of self-care. One participant also referenced going to their place of worship as a form of self-care. They noted that “I’m a nurse so I go to work, I’m a PRN so I go like once a week for a 12-hour shift and that’s kind of it to get away.”
Participants were then asked to describe those self-care behaviors they would ideally like to engage in, given the necessary resources and support. Overall, all participants \((n = 4)\) struggled to respond to this question. In particular, one stated that “…even though we’re trying to do self-care and you know we’re trying to do all these things and take care of ourselves and whatever, sometimes it’s more stress than it’s worth.” However, two participants noted that they would like to be able to spend more time with their children and/or spouse. For example, one indicated that they would like to be able to do more “…activities with my husband…we both get home and split up and do what has to get done… and given that time is so short…there’s not an extra hour in there for us.” Similarly, another participant shared that they would like more one-on-one time with each of their children because “by the time they get home and we get dinner or drive and pick up from practices and then get homework done, there’s not enough time in the day.” One participant discussed wanting to be able to sleep peacefully, stating that “…sleep is relative for me…it’s a 24-hour job, you’re never really off and just we’re always on alert and we’re always on standby.”

Current Support Network. Participants were asked to share who they consider as part of their support network. With regard to who participants considered when thinking of their support network, three themes emerged: family \((n = 3)\), friends \((n = 3)\), and web-based support groups \((n = 3)\). When discussing family, one participant stated: “[My sister] helped me out a lot with pushing for the IEP and stuff like that…once she called in and helped advocate for us…because she knows what she’s talking about, so that was really helpful getting everything in place.” A participant who talked about friends as part of their support network shared: “two of the women that I run with, their kids also have ADHD… and they’re older than mine and so that’s nice because…it is nice to have that connection with them that it’s like, okay, this is
making me crazy, is this normal?” In terms of web-based support, one participant said: “…to me, it’s almost easier that it’s not face-to-face… I mean you get to be anonymous a little bit, and like my son pissed me off today and I feel like are you allowed to say that? That your disabled child pissed you off today?... I mean some days are better than others, but some days you’re just tired and crabby.”

**Helpful and Ideal Types of Social Support.** Participants were also asked to describe the types of support that they find to be most helpful and would, ideally, like more of. Two common themes arose across all participants (n = 4): emotional support and information/resources. With regard to emotional support, one participant said: “… just being able to just vent to someone and say you know and hear it’s like okay…am I a bad mom for sticking to my guns and not giving in and you know that type of thing so it’s the emotional support there is somebody just saying I understand, it was hard for you, it’s okay, you know you’ll get through it.” Another participant indicated that: “I think at this stage of the game…it would be more um emotional support and possibly um because childcare you know we have a little bit more flexibility than we used to right because of their ages um so it’s more emotional support and then having a place to go maybe.” In terms of information/resources, one participant indicated: “I learn a lot from other parents who are out here, like certain diapers and what this works and that didn’t work.” Another shared that: “I just thought it was helpful so far just to get resources and people give their input about medications and things that work and their concerns with the school what’s working what’s not um and then just venting.”

**Integration Phase**

Because Phase One survey and focus group participants identified that many aspects of their existing Facebook support groups were helpful, the intervention group was designed to
mirror these Facebook support groups. However, participants’ desired changes to their Facebook groups were taken into account and guided recruitment, selection of participants, and development of intervention content. For one, geographic region was limited due to the desire to connect with other caregivers in proximity. Given that some participants identified a desire for advice or guidance from professionals, but the majority indicated that they would like a greater connection to other parents/caregivers, the intervention group prioritized connections between participants with information and resources provided by both the researcher and participants.

With regard to the procedures for intervention development and delivery, Phase One results indicated that participants struggled to identify personal needs and goals related to health-promoting self-care, thus further establishing the need for social support as a means of supporting health-promoting self-care. Specifically, Phase One results supported the need for an intervention focused more broadly on health-promoting self-care as opposed to targeting specific health-promoting self-care behaviors for the whole group. Pender and colleagues (2015) discuss that a key component of successful health-promotion interventions is goal setting prior to initiating a new behavior, with goals set by individuals themselves, which is monitored through social support and feedback. As such, it was determined that caregivers would likely benefit from an introduction to goal setting and exposure to information and resources within multiple areas of health-promoting self-care. It was also hypothesized that this would allow caregivers to provide one another with emotional support and information/resources, which were the two types of social support most desired by Phase One participants.

With regard to the length of the intervention pilot, health-promotion and lifestyle interventions for informal caregivers range widely in duration (Sin et al., 2018), but intervention pilots and development studies tend to range from 2 sessions to 12 weeks across Facebook and
in-person delivery (Boots et al., 2017; Oliveira et al., 2019; Ugalde et al., 2018). As a result, it was determined that the intervention would be piloted over an 8-week period given the timeline for recruitment and enrollment lasting from September to mid-October.
Chapter IV: Phase Two Methods and Results

Phase Two Methods

Recruitment

Recruitment information was distributed via dissemination outlets that are accessed by families of children with disabilities. Examples include open Facebook groups for families of children with disabilities, the Connecticut Parent Advocacy Center (CPAC), the Federation for Children with Special Needs (FCSN), and Autism Services & Resources Connecticut (ASRC). The administrators and/or moderators of open Facebook groups were contacted for permission prior to posting the recruitment advertisement in the group. Interested persons were directed to contact the researchers via email and/or to a link to an online Qualtrics survey to identify initial eligibility, collect basic demographic information, and identify interest in further participation. Participants who responded via email were sent the link and instructed to complete the online survey. The Online Survey is available in Appendix A and includes the content and processes for proceeding.

For those participants who met inclusion criteria, the available pool was reviewed to recruit a diverse range of possible intervention participants. Participants who did not meet inclusion criteria were notified immediately via Qualtrics message that they were ineligible and directed to email the student researcher with any questions. Eligible participants who were not selected to participate in the Facebook group were notified via provided email address within 6 weeks of their survey completion.

Participants

A priori power analysis was conducted to determine the necessary sample size to obtain 80% power for detecting a .5 effect size utilizing a .05 statistical significance level. This effect
size was chosen given that other interventions focused on this population have tended to show medium to large effects (Frantz et al., 2018). Results of the power analysis indicated that 34 participants were needed in both the pre-test and post-test groups. Of the caregivers of children with DD who were interested in participating \((N = 133)\), 50 were initially selected to participate in the Facebook group pilot intervention. If a participant did not respond after two contact attempts, they were opted out of the study and a participant with similar demographic characteristics was selected to replace that participant. Of those who were contacted, one participant was no longer interested in participating in the intervention, seven did not return consent, and three did not join the Facebook group. Forty participants joined the Facebook group. Over the course of the eight-week intervention, including pretest and posttest, four participants withdrew from the study and two participants did not complete the posttest. This resulted in a final sample of 34 participants, the majority of whom were female \((n = 33)\). See Tables 3 and 4 for more detailed demographic information about the final sample.

**Materials and Measures**

**Perceived Stress Scale (PSS).** The PSS is a global measure of a person’s feelings about life stressors (Pender et al., 2015). The PSS has been identified as the most widely used measure of perceived stress (Karam et al., 2012), in part due to its availability in 25 different languages and continued validation using diverse samples (Taylor, 2015). Further, the PSS has shown to be a better predictor of caregiver stress compared to traditional measures of caregiver burden (Chwalisz & Kisler, 1995). Given that perceived stress and caregiver burden have not shown to independently predict outcomes for caregivers, with perceived stress predicting more of the variance in both physical and mental health status, the PSS may provide more meaningful
information regarding the physical and mental health of caregivers than other measures (Chwalisz & Kisler, 1995).

The original PSS includes 14 items that measure “the degree to which situations in one’s life are appraised as stressful,” (p. 387, Cohen et al., 1983). However, further factor analyses suggested that four items performed poorly and were subsequently dropped, leading to increased use of the PSS-10, which is a 10-item version of the PSS (Cohen et al., 1983). Of the 10 items, seven items are scored from 0-4; the other seven (items 4, 5, 6, 7, 8, 10, and 13) are positively stated and thus are reverse scored (Cohen et al., 1983). The total PSS score is obtained by adding together the scores for all 14 items. The questions on the PSS were written at a middle school reading level and were designed to be general as to not include content that is specific to any subgroup of the population (Cohen et al., 1983). The scale was initially developed and validated with two samples of college students, with a total of 446 participants aged, on average, between 19.01 and 20.75, and a smoking-cessation sample containing 64 participants with an average age of 38.4 years (Cohen et al., 1983). Findings of the initial study (Cohen et al., 1983) indicated that the PSS demonstrated strong internal reliability across all three sample (coefficient alphas = .84, .85, and .86). Test-retest reliability was assessed with a sample of 82 college students and the smoking cessation sample and indicated strong reliability for the college sample (correlation coefficient = .85) and adequate reliability for the smoking cessation sample (correlation coefficient = .55). Overall, there were no significant differences in the validity criteria across sex or age, with the exception of a strong correlation between PSS score and number of life events for younger participants and little to no correlation for older participants (Cohen et al., 1983).

**Health-Promoting Lifestyle Profile, 2nd Edition (HPLP-II).** The HPLP-II is designed to measure an individual’s health promoting lifestyle overall (Sechrist et al., 1987). Given its
validation using multiple languages and populations, the HPLP-II has continued to be widely used to measure both health behavior and lifestyle changes (Ping et al., 2018). The HPLP-II includes six subscales (health responsibility, physical activity, nutrition, interpersonal relations, spiritual growth, and stress management) comprised of 52 total items (Pender et al., 2015). Each item has four response options (1 = never, 2 = sometimes, 3 = often, 4 = routinely) that measure the frequency of one’s health-promoting behavior (Samuelson et al., 2010; Walker et al., 1988). The mean of the responses to all items is calculated to obtain an overall score and scores for each subscale are calculated using the mean of responses to the items within each subscale (Walker et al., 1995). The resulting score profile provides information that allows practitioners to develop a tailored, individualized plan for health promotion using an individual’s existing lifestyle strengths, resources, and areas for growth (Pender et al., 2015).

The HPLP-II was initially piloted with a sample of 173 undergraduate and graduate nursing students (Walker et al., 1987). Findings of this study indicated high internal consistency (coefficient alpha = .919) and stable test-retest reliability (correlation coefficient = .854). Evidence of content validity was established through a review of each item by four experts in health promotion (Walker et al., 1987). The HPLP-II was then empirically validated with a sample of 952 adults aged 18 to 88 (mean 39.2 years), just over 50% male, with the majority reporting a middle-class income level (Walker et al., 1987). An exploratory factor analysis yielded 16 factors that were combined into six subscales; further analysis confirmed this six-factor solution (Walker et al., 1987).

**Formative Progress Monitoring Measure.** In order to provide formative assessment of progress toward identified health-promoting goals, a single-item scale (linked in Appendix E.2) was created. Using a 5-point scale, participants rated how much progress they made relative to
their self-identified goal, with the lower anchor serving as the baseline level and the highest anchor indicating above expected levels of progress.

**Intervention Fidelity.** A fidelity measure was created based on Pagoto et al. (2016)’s guidance on adapting interventions for social media delivery. This measure assesses fidelity of a social media-delivered intervention based on interventionist and participant posting, commenting, and activity (e.g., log in frequency, number of views each post receives, percentage of planned posts that get posted). The fidelity measure consists of seven open-ended questions for the interventionist to complete and is available in Appendix C.

**Usability.** A modified version of the Usage Rating Profile – Intervention Revised (URP-IR; Chafouleas et al., 2011) was created to assess usability of the Facebook support group intervention (Appendix D). The original instrument, the Usage Rating Profile – Intervention (URP-I; Chafouleas et al., 2009) was designed to assess factors associated with intervention usage in schools (Briesch et al., 2013). In the initial validation of the URP-I, four subscales were identified: acceptability, understanding, feasibility, and system support (Briesch et al., 2013). The validation of the URP-IR indicated six subscales: acceptability, understanding, family-school collaboration, feasibility, system climate, and system support (Briesch et al., 2013).

The URP-IR contains 29 items across these six subscales that are rated on a six-point scale from “strongly disagree” to “strongly agree.” Given that the school-based subscales are not relevant for the purposes of this study, the modified version of the URP-IR only includes items from the acceptability, understanding, and feasibility subscales. Acceptability items assess the extent to which a participant finds the intervention to be acceptable, along with enthusiasm about the intervention (Chafouleas et al., 2011). Feasibility items assess whether a participant perceives the intervention to be feasible to implement considering existing demands (Chafouleas et al.,
Understanding items assess whether a participant understands how to use the intervention based on knowledge of implementation procedures (Chafouleas et al., 2012). Although the URP-IR was validated for use with educators and other individuals responsible for implementing interventions, the assessment purpose, modality, and readability of the items makes it an ideal tool to modify for the present study. To maintain the integrity of the URP-IR, only minor changes were made to the wording of each item and the directions.

**Procedures**

**Intervention Development.** A Facebook group-delivered intervention was developed using both results from Phase One and guidance from Pender and colleagues (2015). Phase One results indicated that caregivers’ needs are broad and diverse, suggesting that a one-size-fits-all intervention would not be sufficient to meet these needs. However, a common theme was that caregivers struggled to identify health-promoting or other self-care behaviors that they currently engage in or would like to increase. This is consistent with the literature reviewed in Chapter 2, which indicates that caregivers often experience difficulty prioritizing their own self-care. As a result, coupled with guidance from Pender and colleagues (2015), it was determined that the intervention would focus on increasing knowledge across broad health-related areas and setting goals related to self-care. The broad health-related areas were adapted from Pender and colleagues (2015) and Chafouleas and colleagues (2020) and included: physical health (e.g., nutrition, exercise, sleep), psychological health (e.g., stress management, anxiety, depression), social health (e.g., social support, relationships), and work health (e.g., balancing work/school with family, time management).

The intervention content related to each of these areas was pulled from sources that delivered information in an accessible format (e.g., infographic, brief article, video). Other
studies using similar methodology posted content that included discussion questions to promote participant communication, challenges and quizzes to promote engagement, informational posts (e.g., news articles, videos, electronic resources), and reminders to complete any necessary intervention steps or components (Ling et al., 2018; Valle et al., 2013); this was also used to guide intervention content development. The outline of content delivery and the intervention content and weekly posts are provided in the Intervention Plan available in Appendix E.1 through Appendix E.9.

**Intervention Delivery.** The Facebook group intervention was piloted over an 8-week period during the fall of 2019. The Facebook group content was both host and user generated, in that the researcher made posts to prompt users to post content. User-generated content was encouraged by weekly prompts posted by the researcher. Participants did not have to post, respond to, or comment publicly in order to qualify as engaged in the intervention. As long as they acknowledged the researcher’s post (or post(s) of another participant) with a reaction, they were counted as engaged. To limit deviations in content delivery, posts were scheduled at the beginning of the week and checked by the researcher at least three times per week to ensure that all content was successfully delivered as planned. In addition, no moderated group chats were held outside of the posts and comments within the group. However, participants were able to contact the researcher via private direct Facebook message or email with questions or concerns about the study.

At the beginning of the intervention, participants were provided with instructions (available in Appendix E.2) for creating goals specific to their self-identified health-promoting self-care needs. During the 8-week period, participants completed a weekly single-item scale to provide a formative, short term evaluation of progress toward identified health-promoting self-
care goals. Participants needed to read and “react” (e.g., like) to at least one post or comment throughout each week. The researcher posted prompts and activities, which could be completed independently/privately or via post in the group. Each activity did not take more than 60 minutes to complete. Participant engagement in the intervention was measured by: (1) at least one demonstration of passive (i.e., reaction to a post, comment, or reply) or active (i.e., post, comment, reply) each week; and (2) completion of each weekly progress rating. The researcher examined participant Facebook group posts throughout the intervention to monitor the frequency and nature of posts. If a participant missed two consecutive weeks, they were contacted via private direct Facebook message to confirm that they still wished to participate in the study. If they did not respond to this message, they were notified that they would not be eligible for the full intervention incentive but were able to stay in the group.

**Data Analysis.** Data analyses for Phase Two primarily included quantitative methods. Specifically, because Phase Two employed a one-group pretest-posttest design, pretest and posttest data were both analyzed independently and then compared to assess differences. Creswell (2014) presents steps for conducting quantitative data analysis that were used to guide Phase Two analyses. First, independent descriptive analyses of pretest and posttest data were conducted for the PSS and HPLP-II. Descriptive analyses were also conducted for the modified URP-IR. Next, the statistical computer program SPSS was used to run statistical analyses. Dependent samples $t$-tests were conducted to determine whether significant differences existed between pretest and posttest scores. Cohen’s (1988) effect size $d$ was used as the effect size statistic for the dependent samples $t$-tests. Raw data from participant weekly progress ratings were analyzed to determine trends over the course of the intervention.
Phase Two Results

Dependent Samples t-Test Analyses

Dependent samples t-tests were conducted to compare self-reported perceived stress and health-promoting self-care from pre-intervention (pretest) to post-intervention (posttest). As shown in Table 5, participant ratings of perceived stress were higher at pretest (M = 23.53, SD = 4.002) than at posttest (M = 21.56, SD = 2.841). As indicated in Table 6, results of the dependent samples t-test are available indicated that the difference in PSS scores is statistically significant, $t(33) = 2.903, p = .007$. The effect size for perceived stress ($d = 0.498$) was just under Cohen’s (1988) criterion for a medium effect ($d = 0.5$). As shown in Table 7, the scores for overall health-promoting self-care were lower at pretest (M = 2.109, SD = 0.466) than at posttest (M = 2.494, SD = 0.506). The results of a dependent samples t-test are available in Table 8 and indicate that the difference in overall HPLP-II from pretest to posttest was statistically significant, $t(33) = 5.909, p = .000$. The effect size for overall health-promoting self-care ($d = 1.013$) was found to exceed Cohen’s (1988) criterion for a large effect ($d = 0.8$).

Dependent samples t-tests were also conducted to compare scores on the six subscales of the HPLP-II between pretest and posttest. As shown in Table 7, health responsibility scores increased from pretest ($M = 1.938, SD = .466$) to posttest ($M = 2.363, SD = .696$). Physical activity scores also increased from pretest ($M = 1.680, SD = .691$) to posttest ($M = 2.132, SD = .692$). Nutrition increased from pretest ($M = 2.271, SD = .608$) to posttest ($M = 2.552, SD = .563$). Spiritual growth increased from pretest ($M = 2.348, SD = .564$) to posttest ($M = 2.748, SD = .617$). Interpersonal relations increased from pretest ($M = 2.480, SD = .589$) to posttest ($M = 2.783, SD = .552$) as well. Finally, stress management increased from pretest ($M = 1.864, SD = .543$) to posttest ($M = 2.338, SD = .586$). As shown in Table 8, across all six subscales, score
differences from pretest to posttest were statistically significant at the $p < .01$ level. Effect sizes for all subscales exceeded Cohen’s (1988) criterion for a medium effect, with stress management also exceeding the criterion for a large effect. These results suggest that self-reported perceived stress significantly decreased and self-reported health-promoting self-care significantly increased following the intervention.

**Intervention Fidelity**

Fidelity of the intervention was assessed using open-ended questions regarding researcher and participant behavior (see Appendix C). In terms of researcher behavior, one hundred percent of planned posts by the researcher were actually posted and the interventionist logged in 3 times per week on average. The researcher reacted to (e.g., “liked”) 25.61% ($n = 94$) of participant posts/comments and replied to (i.e., commented on) 3.27% ($n = 12$) of participant posts/comments. This was by design, as the intention of the group was to have participants form relationships and provide support to one another with minimal interaction from the researcher. In terms of participant engagement, 80% of participants ($n = 40$) who provided consent joined the Facebook intervention group. Each post (researcher- and participant-generated) was viewed by an average of 33.17 participants and, on average, each participant viewed 82.92% of all posts.

**Usability**

Overall, participants rated this intervention positively on the modified URP-IR ($M = 5.007$, $SD = 0.603$), which contained items from the original URP-IR’s acceptability, understanding, and feasibility subscales (see Appendix D). In terms of intervention acceptability, participants on average agreed with statements indicating that they found the intervention to be acceptable and were enthusiastic about the intervention ($M = 5.042$, $SD = 0.587$). With regard to understanding, participants generally agreed with items indicating that they understood how to use the
intervention ($M = 4.980, SD = 0.656$). On the feasibility subscale, participants also generally agreed with statements indicating that the intervention was reasonably easy to use, not too time intensive, and did not require too much preparation ($M = 4.966, SD = 0.744$).

**Self-Reported Weekly Progress**

As shown in Tables 9, 10, and 11, of the 34 participants who completed the intervention, 50% of participants missed zero or one weekly rating ($n = 17$), 32.35% of participants missed two or three weekly ratings ($n = 11$), 8.82% of participants missed four or five weekly ratings ($n = 3$), and 11.76% of participants missed six or seven weekly ratings ($n = 4$). It is of note that Week 6 had the lowest response rate across participants, particularly for those who missed two or three ratings. Table 9 illustrates the weekly self-reported progress ratings for participants who completed either seven or eight ratings. The majority of participants in this category reached a rating of three, or moderate progress, by the fourth week of the intervention, but some participants showed variability in progress ratings across the eight weeks. Table 10 shows the weekly progress ratings for participants who completed between five and six ratings. Similar patterns emerged for this group of participants with regard to variability. However, participants in this group rated their progress as lower overall. For example, in week five, only half of participants who completed ratings indicated moderate progress. By week eight, the majority of participants reported moderate progress, with one participant indicating that they met their goal. As shown in Table 11, among participants who missed four or more weekly ratings ($n = 7$), progress ratings were inconsistent and highly variable.
Chapter V: Discussion

Caregivers of children with DD play a critical role in shaping the physical, social, emotional, behavioral and academic development of the children for whom they provide care (National Academies of Sciences, Engineering, and Medicine, 2019; Pinquart, 2018). As such, caregivers of children with DD need to be mentally, emotionally, and physically healthy in order to fulfill this role effectively (Goudie et al., 2014; Quinn et al., 2013). Given that caregivers of children with DD often experience challenges in these domains as a result of chronic stress (Carroll et al., 2013; Goudie et al., 2014; Lindo et al., 2016; Lovell et al., 2012), it is critical to capitalize on mediators of stress that promote positive outcomes. Health-promoting self-care (i.e., coping) is one such mediator, as is social support (Pearlin et al., 1990). However, given that caregivers of children with DD demonstrate barriers to engaging in health-promoting self-care (Chafouleas et al., 2020) and receiving social support (Carroll 2013), it is critical to identify methods to support caregivers that reduce or remove these barriers. Technology, specifically social media, has shown promise as a means for delivering interventions (DeHoff et al., 2016; Hamm et al., 2013; Laranjo et al., 2014). However, no studies to date have explored Facebook group interventions, which promote peer support, targeting health-promoting self-care for caregivers of children with DD. As such, the purpose of the present study was to develop and pilot a Facebook-delivered health-promoting self-care intervention for caregivers of children with DD. Using an exploratory sequential mixed methods design, information and feedback from caregivers of children with DD were analyzed qualitatively and used to develop the intervention content, which was then piloted and evaluated quantitatively.
Characteristics of Caregivers of Children with DD

The first research question explored the characteristics of caregivers of children with DD who participate in Facebook support groups. The majority of survey participants identified as female, were between the ages of 35 and 44, were married or in a domestic partnership, and were white/non-Hispanic. Over half of participants had earned a bachelor’s degree or advanced degree, with an annual household income of at least $75,000. Participants most frequently reported working full time or part time. Finally, a majority of participants were the parents of the child(ren) for whom they provide care and shared caregiving responsibilities with a spouse or partner. Over 60% of participants’ children were male, and ranged in age from three to twenty-one, were diagnosed with a DD between birth and age 15 and were most frequently diagnosed with multiple disabilities. These characteristics are fairly consistent with the demographics of participants of studies focused on caregivers of children with DD (Barros et al., 2019; Chafouleas et al., 2020; Hoefman et al., 2014; Iacob et al., 2020; Lindo et al., 2016; Stuart & McGrew, 2009) and thus may be a reflection of the characteristics of caregivers who are interested and willing in participating in research studies as opposed to those specifically participating in Facebook groups.

Survey participants reported experiencing burden in some areas as a result of caregiving. As others have found (McManus et al., 2011), participants indicated that interruption of their time was most heavily impacted by their role as a caregiver. In addition, difficulties balancing multiple roles (e.g., work, other duties), disruption of routines and social activities, and feelings of isolation were reported by participants as impacted by caregiving. These challenges are consistent with findings from studies focused on caregivers of other populations (Acton, 2002;
Family Caregiver Alliance, 2012), as well as caregivers of children with DD (Brannan & Heflinger, 2006; Caldwell, 2008; Murphy et al., 2006; Resch et al., 2010).

In terms of Facebook support groups, the majority of survey participants infrequently (i.e., less than once per month) engaged in active participation (e.g., posting in the group, commenting on others’ posts) in the group. Most often, participants passively participated (e.g., reading others’ posts, multiple times per week. Findings on participant-reported benefits of participating in a Facebook support group are consistent with prior research indicating that caregivers of children with DD use Facebook to receive social support and report benefitting from this support (Chafouleas et al., 2020; Cole et al., 2017; Gerber, 2014; Niela-Vilen et al., 2014). As researchers have found with regard to in-person support groups (Baum, 2004; Carroll, 2013; Solomon, et al., 2001), participants reported that a benefit of participating in a Facebook support group is the ability to connect with others who have similar experiences. With regard to ideal improvements to their current Facebook support group, responses varied but included a greater connection with other parents, in-person events or activities to accompany the online support, a resource directory, content more specific to their town or geographic area, and advice from professionals.

**Caregiver Experiences and Needs**

The second research question evaluated caregivers’ experiences and needs around stress, health-promoting self-care, and social support. Focus group participants indicated stressors such as time commitments associated with caregiving, navigating appointments with multiple professionals (e.g., doctors, educators, therapists, insurance companies), and feelings of judgment or social isolation. Participants reported that these stressors primarily impacted their mental and emotional well-being, but also discussed an impact on their physical health in terms
of exhaustion and sleep difficulties. These experiences of stress have commonly been identified by caregivers of children with DD throughout the literature (Chafouleas et al., 2020; Iadarola et al., 2019).

Results were consistent with prior research illustrating that engaging in health-promoting self-care is challenging as a result of the stressors associated with caregiving (Carroll, 2013; Chafouleas et al., 2020; Iadarola et al., 2019). Specifically, participants struggled to identify self-care behaviors that they would ideally like to engage in more frequently if provided the necessary resources and support. This aligns with the findings of Iadarola and colleagues (2019), who found that caregivers reported prioritizing their children with ASD above themselves, which extended to include sacrificing their own self-care. However, some participants did note a desire to have more time to spend with their spouse or individual children and one participant discussed wanting to improve her quality of sleep. Similar to the findings of Chafouleas and colleagues (2020), participants’ self-care ideals were primarily focused on others.

With regard to social support, participants identified family, friends, and web-based support groups (primarily Facebook) as their support network. There was minimal discussion of respite care as a helpful or ideal source of support, which is interesting given that other studies have found respite to be a beneficial support for caregivers of children with DD (Carroll et al., 2013; Murphy et al., 2006). Support provided by family members was noted to be helpful when family could provide information/resources related to their child with a disability (i.e., assistance with navigating the special education process). Participants indicated that the most helpful types of support provided by their support network were emotional support and information and resources. In terms of emotional support, participants identified that it was especially helpful to be able to connect with other caregivers of children with DD, both online and in person. This
provides additional support for findings indicating that social support from sources outside the family may be more strongly associated with positive outcomes than support from family members (Iacob et al., 2020).

**Participant Stress and Self-Care Outcomes**

The third research question examined whether intervention participants experienced changes in perceived stress and health-promoting self-care. There was a significant decrease in participants’ scores on the PSS and a significant increase in participants’ scores on the total and all domains of the HPLP-II. This indicates that overall, participants reported lower levels of perceived stress and higher levels of health-promoting self-care after the 8-week Facebook-delivered intervention. All differences were statistically significant, but within the HPLP-II subscales participants reported the greatest gains with regard to stress management, spiritual growth, and physical activity and the least improvement with behaviors related to nutrition. Overall, medium to large effect sizes (Cohen, 1988) were indicated for all pretest to posttest differences. Although this is the first study exploring the impact of a Facebook group-delivered intervention on stress and health-promoting self-care and the first evaluation of the intervention developed as part of this study, another intervention study targeting this population also found medium to large effects (Musil et al., 2015). As such, it may be the case that the substantial effect sizes are due to participants’ desire and ability to participate in an intervention as opposed to the intervention itself having a large effect on health-promoting self-care.

**Intervention Usability**

The fourth research question evaluated how intervention participants perceived the usability of the intervention. Overall, participants indicated that the Facebook-delivered intervention was feasible, usable, and acceptable. Specifically, all mean subscale scores indicated agreement with
the statements within those subscales. This finding is consistent with prior research that indicates participants have found Facebook groups to be easy to use, beneficial, and supportive (Parker Oliver et al., 2015). Further, this provides additional support for the use of “secret” Facebook groups as a promising mode of intervention delivery (Naslund et al., 2018).

**Self-Reported Progress**

Finally, an exploratory research question examined whether differences existed in intervention participants’ weekly self-reported progress toward their goals. Overall, across participant groups, results indicate that participants who completed a greater number of weekly ratings demonstrated more progress toward their goal than participants who completed fewer ratings. This is consistent with findings indicating that participants of Facebook group interventions who demonstrate more engagement show greater improvements (Naslund et al., 2018). However, even for those participants who completed the most ratings, there was some variability both within participants and across weeks. For example, some participants demonstrated an increase followed by a plateau, some indicated a plateau followed by a jump in rating, and others reported moving back to their baseline level at different points during the intervention. Further, although all participants were instructed to rate present level for the first weekly rating, 14 of the 34 participants provided a rating other than one, with one participant providing a rating of three and 13 participants providing a rating of two. It is unknown as to why these participants did not indicate a rating of present level at the start of the intervention.

**Limitations**

Due to difficulty with recruitment and attrition in Phase One, the sample for the focus groups was much smaller than intended. As a result, there was a lack of diversity in caregiver and child characteristics present in the focus group data. In addition, the procedures for conducting the
focus groups might have limited qualitative analysis and conclusions that were drawn. Specifically, the focus groups were conducted virtually without video, which did not allow for reading or responding to participant non-verbal cues.

Shadish, Cook, and Campbell (2002) define threats to internal, external, construct, and statistical conclusion validity for quasi-experimental research. A number of factors within each of these areas may threaten the validity of this study. With regard to internal validity, history, statistical regression, and testing may have threatened the study’s validity. For history, events that occurred during the course of the intervention could have impacted participants’ response to the intervention. Given that caregivers of children with DD have shown to increased challenges compared to caregivers of children who are typically developing, it is possible that statistical regression to the mean threatened the internal validity of the study. In terms of testing, it is possible that participant responses on the posttest were affected by the pretest. In other words, the difference in participant responses to posttest items compared to their responses to pretest items could have been a result of the pretest, or an interaction of the pretest and intervention, as opposed to a result of the intervention.

In terms of external validity, generalizability is the largest threat. Given that this is an exploratory study, the small sample size and participant selection for the focus groups and intervention pilot both limit the generalizability of study findings across populations and settings. Further, use of a one-group pretest-posttest design limits the conclusions that can be drawn. Although the difference between pretest and posttest scores were statistically significant, the design does not allow for determining whether there was a significant effect of the intervention on perceived stress and health-promoting self-care (Knapp, 2016). Another possible threat to validity is the potential for response bias, particularly regarding the initial recruitment surveys.
for both phases. In particular, those who participated in the intervention may have already been interested in health-promoting self-care or were motivated to engage in health-promoting self-care and thus showed a greater change than would be present among the general population of caregivers of children with DD. In addition, usability results may not generalize to participants who are not proficient in or regular users of Facebook.

Threats to construct validity also may have been present. For one, experimenter expectancies could have had an impact on validity. Participants may have understood the desired outcome for the study, and/or the researcher’s actions may have inadvertently biased the results of the study. Given that all outcome variables were assessed using self-report, mono-method bias may have impacted construct validity. Further, the present study relied solely on self-report, which carries disadvantages such as the potential for social desirability bias, the participant’s mood at the time of completing a measure, and misunderstanding of the instructions of measures, which can all impact validity. Since stress and health-promoting self-care were each measured using only one operationalization of each construct, mono-operation bias may threaten the study’s validity. Further, the use of only two measures limited the conclusions that are able to be drawn from the present study. In addition, the single-item scale that was created for this study has no known psychometric properties. Finally, reactive self-report changes may threaten the construct validity of the study. Specifically, the posttest questions may have prompted a response from participants that may not have occurred naturally. Finally, statistical problems may threaten the validity of this study. In Phase Two, the quantitative variables violated the assumptions of multiple analyses given their primarily ordinal and categorical nature. Therefore, the extent of exploratory analyses was largely limited to descriptive statistics.
Future Directions for Research

Although these results are promising, given that this was an intervention development study, further research is needed to establish the effectiveness of the intervention. Future directions include replicating the delivery of this intervention to determine whether the same outcomes would occur with a different sample of caregivers of children with DD, with other populations, and using different delivery methods (e.g., hybrid online and in person, in person only). In addition, future studies should attempt to recruit a more culturally, socially, and economically diverse sample of caregivers of children with DD to allow for determining implications and recommendations for supports that would appropriately meet their needs.

To conduct a more rigorous evaluation of the intervention, future studies should incorporate a control group to better identify whether changes from pretest to posttest are a result of the intervention and would not otherwise occur. Further, adding a second posttest after a time delay could provide information as to whether participants maintain changes following the intervention. Given that participants demonstrated improved outcomes at the end of this intervention, future studies could explore whether social support or health-promoting self-care is the more important component of the intervention, or if they are equally important. In addition, future work could be more robust and explore inter-generational effects (e.g., child outcomes) of the intervention. Future research could also focus more explicitly on goal setting and goal attainment as part of health-promoting self-care interventions for caregivers of children with DD, such as evaluating the content and quality of goals set by participants along with use of a formal goal attainment scale. Given that participants’ reported progress largely plateaued after week 4, further exploration is also needed to determine the ideal number of weeks.
Conclusion and Implications

Taken together, Phase One participant responses suggested a need for intervention related to their health-promoting self-care. Phase Two participants largely responded favorably to the intervention, reporting decreased stress and increased health-promoting self-care behaviors. In addition, these participants found the intervention to be highly usable. Despite limitations, the intervention developed in the present study shows promise to become an effective, usable method to support caregivers of children with DD in reducing stress and increasing health-promoting self-care.

Overall, the sample of caregivers was primarily white women from middle to high socioeconomic backgrounds. Given that these participants reported experiencing significant challenges related to the stress of caring for a child with a DD and barriers to engaging in health-promoting self-care, it is likely that individuals with fewer resources experience even more significant challenges. In fact, recent findings with regard to stress in parents of children with ASD who are non-white, speak Spanish, and are lower income and/or living in a rural area indicate that race, ethnicity, language, and income impact their stress experience (Iadarola et al., 2019). As such, the experiences of caregivers of children with DD that were used to develop the intervention in this study may not generalize to other caregivers. Therefore, it is unknown whether the intervention is appropriate for meeting the needs of culturally, linguistically, and socioeconomically diverse caregivers of children with DD.

Interestingly, despite the difference in perceived stress having the lowest effect size of all pretest to posttest differences, the domain of the HPLP-II with the largest effect size was stress management. This suggests that participants experienced a greater change with regard to stress management behaviors that perception of their stress experience, which was anticipated given
that the intervention was focused on behavior change related to health-promoting self-care.

Although the content of participant goals is unknown, this may indicate that participants
developed personal goals around stress management. Further evaluation of the goal setting
component of the intervention would allow for greater understanding and interpretation of pretest
to posttest differences.

Given the minimal interaction between the researcher and participants, the Facebook group
relied on participant-generated responses and peer support. Although the researcher shared
information and provided prompts for participant engagement, the lack of emotional support
provided by the researcher to participants indicates that perhaps caregivers of children with DD
benefit from access to information and peer support without needing direct support from an
interventionist. As this structure mimics that of Facebook support groups as identified by Phase
One participants, there may be an opportunity for professionals to provide indirect support to
caregivers of children with DD using existing Facebook support groups. For example, a mental
or behavioral health professional could consult with the administrator or moderator of an existing
Facebook support group to provide resources and information that is then shared in the group by
the administrator or moderator.
References


service use and interest in support services among distressed family caregivers of lung cancer patients. *Psycho-Oncology*, 22, 1549-1556.


Table 1  
*Phase One Survey Participant and Child Characteristics as a Percentage of the Sample*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td><strong>Age (N = 39)</strong></td>
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</tr>
<tr>
<td>25-34</td>
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<td>25.6%</td>
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<tr>
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<td>45-54</td>
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</tr>
<tr>
<td>55-64</td>
<td>4</td>
<td>10.3%</td>
</tr>
<tr>
<td><strong>Gender (N = 39)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>2.6%</td>
</tr>
<tr>
<td>Female</td>
<td>38</td>
<td>97.4%</td>
</tr>
<tr>
<td><strong>Race (N = 39)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>2</td>
<td>5.1%</td>
</tr>
<tr>
<td>White</td>
<td>35</td>
<td>89.7%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.6%</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1</td>
<td>2.6%</td>
</tr>
<tr>
<td><strong>Ethnicity (N = 38)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>2.6%</td>
</tr>
<tr>
<td>Not Hispanic</td>
<td>35</td>
<td>89.7%</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>2</td>
<td>5.1%</td>
</tr>
<tr>
<td><strong>Level of Education (N = 39)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>2</td>
<td>5.1%</td>
</tr>
<tr>
<td>Some college</td>
<td>8</td>
<td>20.5%</td>
</tr>
<tr>
<td>Associates</td>
<td>4</td>
<td>10.3%</td>
</tr>
<tr>
<td>Bachelors</td>
<td>14</td>
<td>35.9%</td>
</tr>
<tr>
<td>Masters</td>
<td>10</td>
<td>25.6%</td>
</tr>
<tr>
<td>Doctorate</td>
<td>1</td>
<td>2.6%</td>
</tr>
<tr>
<td><strong>Income (N = 39)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>2</td>
<td>5.1%</td>
</tr>
<tr>
<td>$20,000-34,999</td>
<td>5</td>
<td>12.8%</td>
</tr>
<tr>
<td>$35,000-49,999</td>
<td>3</td>
<td>7.7%</td>
</tr>
<tr>
<td>Income Range</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------</td>
<td>------------</td>
</tr>
<tr>
<td>$50,000-74,999</td>
<td>5</td>
<td>12.8%</td>
</tr>
<tr>
<td>$75,000-99,999</td>
<td>9</td>
<td>23.1%</td>
</tr>
<tr>
<td>$100,000-$149,999</td>
<td>6</td>
<td>15.4%</td>
</tr>
<tr>
<td>$150,000 or above</td>
<td>9</td>
<td>23.1%</td>
</tr>
</tbody>
</table>

**Marital Status (N = 39)**
- Single: 2 (5.1%)
- Married/Domestic Partnership: 32 (82.1%)
- Widowed: 1 (2.6%)
- Divorced: 3 (7.7%)
- Separated: 1 (2.6%)

**Employment Status (N = 39)**
- Full Time: 16 (41%)
- Part Time: 11 (28.2%)
- Unemployed – looking: 2 (5.1%)
- Student: 1 (2.6%)
- Homemaker: 8 (20.5%)
- Unable to work: 1 (2.6%)

**Sole Provider of Care for Child (N = 39)**
- Yes: 14 (35.9%)
- No: 25 (64.1%)

**Who Shares Caregiving Responsibilities (N = 25)**
- Spouse/Partner: 23 (92.0%)
- Parent: 1 (4%)
- Other: 1 (4%)

**Relationship to Child (N = 38)**
- Parent: 36 (92.3%)
- Grandparent: 2 (5.3%)

**Child Disability Diagnosis (N = 39)**
- Developmental Delay: 1 (2.6%)
- Autism Spectrum Disorder: 4 (10.3%)
- Attention Deficit/Hyperactivity Disorder: 5 (12.8%)
- Cerebral Palsy: 2 (5.1%)
- Communication Disorder: 2 (5.1%)
<table>
<thead>
<tr>
<th>Condition</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizures/Epilepsy</td>
<td>1</td>
<td>2.6%</td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>24</td>
<td>61.5%</td>
</tr>
</tbody>
</table>

**Child Gender (N = 39)**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>25</td>
<td>64.1%</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>35.9%</td>
</tr>
</tbody>
</table>

**Active Facebook Participation (N = 39)**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than once per month</td>
<td>18</td>
<td>46.2%</td>
</tr>
<tr>
<td>1-4 times per month</td>
<td>8</td>
<td>20.5%</td>
</tr>
<tr>
<td>One time per week</td>
<td>7</td>
<td>17.9%</td>
</tr>
<tr>
<td>2-5 times per week</td>
<td>5</td>
<td>12.8%</td>
</tr>
<tr>
<td>Once daily</td>
<td>1</td>
<td>2.6%</td>
</tr>
</tbody>
</table>

**Passive Facebook Participation (N = 39)**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than once per month</td>
<td>3</td>
<td>7.7%</td>
</tr>
<tr>
<td>1-4 times per month</td>
<td>7</td>
<td>17.9%</td>
</tr>
<tr>
<td>Every other week</td>
<td>1</td>
<td>2.6%</td>
</tr>
<tr>
<td>One time per week</td>
<td>4</td>
<td>10.3%</td>
</tr>
<tr>
<td>2-5 times per week</td>
<td>13</td>
<td>33.3%</td>
</tr>
<tr>
<td>Once daily</td>
<td>4</td>
<td>10.3%</td>
</tr>
<tr>
<td>Multiple times per day</td>
<td>7</td>
<td>17.9%</td>
</tr>
</tbody>
</table>
Table 2.  
*Phase One Continuous Demographic Variables*

<table>
<thead>
<tr>
<th>Variables</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Age ((N = 38))</td>
<td>9.89</td>
<td>5.755</td>
<td>3-21</td>
</tr>
<tr>
<td>Age at Diagnosis ((N = 39))</td>
<td>2.43</td>
<td>3.144</td>
<td>0-15</td>
</tr>
<tr>
<td>Caregiver Burden ((N = 39))</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time interrupted</td>
<td>4.03</td>
<td>.986</td>
<td>2-5</td>
</tr>
<tr>
<td>Missing work/responsibilities</td>
<td>3.54</td>
<td>1.144</td>
<td>1-5</td>
</tr>
<tr>
<td>Family routines disrupted</td>
<td>3.49</td>
<td>1.073</td>
<td>1-5</td>
</tr>
<tr>
<td>Anyone in family having to do without</td>
<td>2.74</td>
<td>1.499</td>
<td>1-5</td>
</tr>
<tr>
<td>Negative mental or physical health effects</td>
<td>2.79</td>
<td>1.281</td>
<td>1-5</td>
</tr>
<tr>
<td>Financial challenges for the family</td>
<td>2.62</td>
<td>1.444</td>
<td>1-5</td>
</tr>
<tr>
<td>Relationship challenges in the family</td>
<td>2.64</td>
<td>1.386</td>
<td>1-5</td>
</tr>
<tr>
<td>Challenges around social activities</td>
<td>3.28</td>
<td>1.376</td>
<td>1-5</td>
</tr>
<tr>
<td>Feelings of isolation</td>
<td>3.31</td>
<td>1.379</td>
<td>1-5</td>
</tr>
</tbody>
</table>

*Note.* Burden items adapted from Brannan et al. (1997). Items scaled from 1 (*not a problem*) to 5 (*very much a problem*).
Table 3.
*Phase Two Survey Participant and Child Characteristics as a Percentage of the Sample*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>7</td>
<td>20.6%</td>
</tr>
<tr>
<td>35-44</td>
<td>17</td>
<td>50.0%</td>
</tr>
<tr>
<td>45-54</td>
<td>7</td>
<td>20.6%</td>
</tr>
<tr>
<td>55-64</td>
<td>2</td>
<td>5.9%</td>
</tr>
<tr>
<td>65-74</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td><strong>Gender (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Female</td>
<td>33</td>
<td>97.1%</td>
</tr>
<tr>
<td><strong>Race (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
<td>11.8%</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>White</td>
<td>25</td>
<td>73.5%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Bi/Multi-Racial</td>
<td>2</td>
<td>5.9%</td>
</tr>
<tr>
<td><strong>Ethnicity (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>4</td>
<td>11.8%</td>
</tr>
<tr>
<td>Not Hispanic</td>
<td>28</td>
<td>82.4%</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>2</td>
<td>5.9%</td>
</tr>
<tr>
<td><strong>Level of Education (N = 33)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>High school</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Some college</td>
<td>4</td>
<td>11.8%</td>
</tr>
<tr>
<td>Associates</td>
<td>4</td>
<td>11.8%</td>
</tr>
<tr>
<td>Bachelors</td>
<td>14</td>
<td>41.2%</td>
</tr>
<tr>
<td>Masters</td>
<td>3</td>
<td>9.1%</td>
</tr>
<tr>
<td>Professional degree</td>
<td>3</td>
<td>9.1%</td>
</tr>
<tr>
<td>Doctorate</td>
<td>3</td>
<td>9.1%</td>
</tr>
<tr>
<td>-----------</td>
<td>---</td>
<td>------</td>
</tr>
<tr>
<td><strong>Income (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>$20,000-34,999</td>
<td>5</td>
<td>14.7%</td>
</tr>
<tr>
<td>$35,000-49,999</td>
<td>4</td>
<td>11.8%</td>
</tr>
<tr>
<td>$50,000-74,999</td>
<td>5</td>
<td>14.7%</td>
</tr>
<tr>
<td>$75,000-99,999</td>
<td>4</td>
<td>11.8%</td>
</tr>
<tr>
<td>$100,000-$149,999</td>
<td>10</td>
<td>29.4%</td>
</tr>
<tr>
<td>$150,000 or above</td>
<td>5</td>
<td>14.7%</td>
</tr>
<tr>
<td><strong>Marital Status (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>7</td>
<td>20.6%</td>
</tr>
<tr>
<td>Married/Domestic Partnership</td>
<td>23</td>
<td>67.6%</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
<td>5.9%</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td><strong>Employment Status (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full Time</td>
<td>12</td>
<td>35.3%</td>
</tr>
<tr>
<td>Part Time</td>
<td>7</td>
<td>20.6%</td>
</tr>
<tr>
<td>Unemployed – looking</td>
<td>2</td>
<td>5.9%</td>
</tr>
<tr>
<td>Unemployed – not looking</td>
<td>3</td>
<td>8.8%</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>5</td>
<td>14.7%</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>2</td>
<td>5.9%</td>
</tr>
<tr>
<td>Unable to work</td>
<td>2</td>
<td>5.9%</td>
</tr>
<tr>
<td><strong>Sole Provider of Care for Child (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>38.2%</td>
</tr>
<tr>
<td>No</td>
<td>21</td>
<td>61.8%</td>
</tr>
<tr>
<td><strong>Who Shares Caregiving Responsibilities (N = 21)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>20</td>
<td>95.2%</td>
</tr>
<tr>
<td>Parent</td>
<td>1</td>
<td>4.8%</td>
</tr>
<tr>
<td><strong>Relationship to Child (N = 34)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>32</td>
<td>94.1%</td>
</tr>
<tr>
<td>Grandparent</td>
<td>2</td>
<td>5.9%</td>
</tr>
</tbody>
</table>
Child Disability Diagnosis ($N = 34$)
- Autism Spectrum Disorder: 11, 32.4%
- Attention Deficit/Hyperactivity Disorder: 1, 2.9%
- Learning Disability: 1, 2.9%
- Multiple Disabilities: 21, 61.8%

Child Gender ($N = 34$)
- Male: 22, 64.7%
- Female: 11, 32.4%
- Other: 1, 2.9%

<table>
<thead>
<tr>
<th>Table 4.</th>
<th>\textit{Phase Two Continuous Demographic Variables}</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables</td>
<td>\textit{M}</td>
</tr>
<tr>
<td>\textbf{Child Characteristics}</td>
<td></td>
</tr>
<tr>
<td>\textit{Child Age (N = 34)}</td>
<td>11.21</td>
</tr>
<tr>
<td>\textit{Age at Diagnosis (N = 34)}</td>
<td>2.62</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 5.</th>
<th>\textit{Descriptive Statistics for the Perceived Stress Scale (PSS)}</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
<td>\textit{M}</td>
</tr>
<tr>
<td>\textit{Pretest Perceived Stress (PSS)}</td>
<td>23.53</td>
</tr>
<tr>
<td>\textit{Posttest Perceived Stress (PSS)}</td>
<td>21.56</td>
</tr>
</tbody>
</table>
Table 6.
**Dependent Samples t-Tests for the Perceived Stress Scale (PSS)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>Std. Error</th>
<th>Std. Mean</th>
<th>95% CI</th>
<th>t</th>
<th>df</th>
<th>Sig (2-tailed)</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Stress (PSS)</td>
<td>1.971</td>
<td>3.958</td>
<td>0.679</td>
<td>0.590</td>
<td>3.352</td>
<td>2.903</td>
<td>33</td>
<td>.007*</td>
<td>0.498</td>
</tr>
</tbody>
</table>

*=Statistically significant at p<.05 level
**=Statistically significant at p<.01 level

Table 7.
**Descriptive Statistics for the Health-Promoting Lifestyle Profile – II (HPLP-II)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pretest Health-Promoting Self-Care (HPLP-II)</td>
<td>2.109</td>
<td>0.466</td>
<td>1.423-3.019</td>
</tr>
<tr>
<td>Health Responsibility</td>
<td>1.938</td>
<td>0.653</td>
<td>1-3.444</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>1.680</td>
<td>0.691</td>
<td>1-3.625</td>
</tr>
<tr>
<td>Nutrition</td>
<td>2.271</td>
<td>0.608</td>
<td>1.222-3.333</td>
</tr>
<tr>
<td>Spiritual Growth</td>
<td>2.348</td>
<td>0.564</td>
<td>1.333-3.667</td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td>2.480</td>
<td>0.589</td>
<td>1.556-4</td>
</tr>
<tr>
<td>Stress Management</td>
<td>1.864</td>
<td>0.543</td>
<td>1.125-3</td>
</tr>
<tr>
<td>Posttest Health-Promoting Self-Care (HPLP-II)</td>
<td>2.494</td>
<td>0.506</td>
<td>1.673-3.635</td>
</tr>
<tr>
<td>Health Responsibility</td>
<td>2.363</td>
<td>0.696</td>
<td>1.333-3.778</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>2.132</td>
<td>0.692</td>
<td>1-3.375</td>
</tr>
<tr>
<td>Nutrition</td>
<td>2.552</td>
<td>0.563</td>
<td>1.333-3.889</td>
</tr>
<tr>
<td>Spiritual Growth</td>
<td>2.748</td>
<td>0.617</td>
<td>1.778-4</td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td>2.783</td>
<td>0.552</td>
<td>1.875-4</td>
</tr>
<tr>
<td>Stress Management</td>
<td>2.338</td>
<td>0.586</td>
<td>1.250-3.875</td>
</tr>
</tbody>
</table>
### Table 8.
**Dependent Samples t-Tests for the Health-Promoting Lifestyle Profile – II (HPLP-II)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>Std. Error Mean</th>
<th>95% CI</th>
<th>t</th>
<th>df</th>
<th>Sig (2-tailed)</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower</td>
<td>Upper</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall Health-Promoting Self-Care (HPLP-II)</td>
<td>0.385</td>
<td>0.380</td>
<td>0.065</td>
<td>0.518</td>
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*=Statistically significant at p<.05 level
**=Statistically significant at p<.01 level
Table 9.
Weekly Self-Reported Progress for Participants Who Completed 7-8 Ratings

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*Notes. Rating of 1 = present level, 2 = minimal progress, 3 = moderate progress, 4 = goal, 5 = above goal. “--” indicates no response.*
**Table 10.**  
*Weekly Self-Reported Progress for Participants Who Completed 5-6 Ratings*

<table>
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*Notes.* Rating of 1 = present level, 2 = minimal progress, 3 = moderate progress, 4 = goal, 5 = above goal. “--” indicates no response.

**Table 11.**  
*Weekly Self-Reported Progress for Participants Who Completed 1-4 Ratings*

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</table>

*Notes.* “--” indicates no response.
Figure 1. Theoretical Framework: An Adaptation of the Stress Process Model of Caregiving (SPMC; Pearlin et al., 1990).

**Background /Context:**
- Caring for a Child with DD
- SES
- Social Network

**Stressors:**
- Child Characteristics (behavior, medical needs)
- Caregiving Responsibilities
- Financial Challenges
- Marital/Family/Relational Conflict
- Work/Occupational Challenges

**Mediators:**
- Social Support
- Health-Promoting Self-Care

**Negative Outcomes:**
- Physical and Psychological Health Challenges

**Positive Outcomes:**
- Increased Physical and Psychological Health
- Decreased Stress
APPENDIX A.1

Phase One Demographic Survey

Inclusion Criteria:

1. Are you the primary caregiver of an individual with a developmental disability?
   a. Yes
      (if Yes) Are you the sole provider of care for this child?
         Yes
         No
      (if No) Who shares caregiving responsibilities with you?
         Spouse/Partner
         Sibling
         Parent
         Other: text box
   b. No

2. Is the individual you are caring for currently between 3 and 21 years of age?
   a. Yes
   b. No

3. Which of the following disability diagnoses have been given to the child you care for?
   a. Developmental Delay
   b. Autism Spectrum Disorder
   c. Intellectual Disability (including Down Syndrome)
   d. Attention Deficit/Hyperactivity Disorder
   e. Learning Disability
   f. Cerebral Palsy
   g. Deaf/Hard of Hearing
   h. Blindness
   i. Stuttering/Stammering
   j. Seizures
   k. Other: text box

Note: Questions are programmed so that a NO answer to 1 or 2 will not continue questions, as a person has not met inclusion criteria. If no box is checked in response to question 3, the person also has not met inclusion criteria as it is unclear as to whether developmental disability is present/understood.

If an inclusion criterion has not been met, a screen will be provided indicating: “We appreciate your interest. At this time, you are not eligible to participate in this research study. If you have any questions, you can contact the researcher at emily.auerbach@uconn.edu. Thank you.”

If all inclusion criteria are met, the person will be directed to a new screen containing an information sheet for participation in the online demographic survey and an option to either continue on or exit the survey. If a person chooses to exit, then a “thank you” screen will appear. If a person chooses to continue on, they will proceed through the next questions.
Caregiver Demographics:

4. What is your relationship to the child with a developmental disability that you care for?
   a. Parent
   b. Grandparent
   c. Guardian
   d. Other: text box

5. What is your age?
   a. Under 18
   b. 18-24 years old
   c. 25-34 years old
   d. 35-44 years old
   e. 45-54 years old
   f. 55-64 years old
   g. 65-74 years old
   h. 75 or older

6. What is your gender/gender identity?
   a. Male
   b. Female
   c. Other: text box – non-required field
   d. Prefer not to say

7. What category best describes your ethnicity?
   a. Hispanic, Latino, or Spanish origin
      i. Mexican, Mexican American, Chicano
      ii. Puerto Rican
      iii. Cuban
      iv. Other: text box
   b. Not of Hispanic, Latino, or Spanish origin
   c. Prefer not to say

8. What category/categories best describes your race?
   a. American Indian/Alaska Native
   b. Asian
   c. Black or African American
   d. Native Hawaiian/Other Pacific Islander
   e. White/Caucasian
   f. Other: text box
   g. Prefer not to say

9. What is your level of education?
   a. Less than a high school diploma
   b. High school degree or equivalent (e.g., GED)
   c. Some college, no degree
   d. Associate degree (e.g., AA, AS)
   e. Bachelor’s degree (e.g., BA, BS)
   f. Master’s degree (e.g., MA, MS, MEd)
   g. Professional degree (e.g., MD, DDS, DVM)
   h. Doctorate (e.g., PhD, EdD)

10. What is your annual household income?
a. Less than $20,000
b. $20,000 to $34,999
c. $35,000 to $49,999
d. $50,000 to $74,999
e. $75,000 to $99,999
f. $100,000 to $149,999
g. Over $150,000

11. What is your marital status?
   a. Single (never married)
   b. Married, or in a domestic partnership
   c. Widowed
   d. Divorced
   e. Separated
   f. Other: text box

12. What is your current employment status?
   a. Employed full time (40 or more hours per week)
   b. Employed part time (up to 39 hours per week)
   c. Unemployed and currently looking for work
   d. Unemployed and not currently looking for work
   e. Student
   f. Retired
   g. Homemaker
   h. Self-employed
   i. Unable to work

**Child Demographics:**

13. What is the current age of the child with a developmental disability that you care for?
   a. Dropdown ranging from 3y 0m to 21y 11m

14. What is the gender of the child with a developmental disability that you care for?
   a. Male
   b. Female
   c. Other

15. At what age did the child you care for first receive diagnosis of a developmental disability?
   a. Dropdown ranging from 0 to 21

16. Does the child with a developmental disability that you care for regularly attend daycare or school?
   a. Yes
      (If Yes) Approximately how many hours per weekday is your child at daycare or in school?
      Dropdown ranging from “Less than 1 hour” to “10 or more hours”
      Does your child have an Individualized Education Program (IEP)?
      Yes
      No
      Does your child have a 504 Plan?
      Yes
No
b. No

Facebook Participation:
17. What is the name of the primary Facebook group you belong to?
18. How often do you actively participate (i.e., create posts, comment on others’ posts) in [Facebook group name]?
19. How often do you passively participate (i.e., “like” or react to others’ posts, read others’ posts) in [Facebook group name]?
20. What is the purpose of [Facebook group name]?
21. What do you perceive to be most helpful about participating in [Facebook group name]?
22. What, if anything, would increase the benefits of participating in [Facebook group name]?

Focus Group Interest:
23. Would you be interested in participating in a focus group that seeks to understand how to best support caregivers of children with developmental disabilities using Facebook?
   a. Yes
      i. (If Yes) Will be directed to the focus group information sheet. Participants will be asked to select whether they are interested in proceeding after reviewing the information sheet. If they are not interested, the participant will be exited from the survey and directed to a “thank you” message. If they are interested, they will proceed to the following questions:
      ii. What is your name?
      iii. What is the best way to contact you about your participation in a focus group?
          1. Phone
          2. Email
          3. Other
      iv. Please select the best days/times for you to participate in a focus group:
          1. Monday
             a. Time 1
             b. Time 2
          2. Tuesday
             a. Time 1
             b. Time 2
          3. Wednesday
             a. Time 1
             b. Time 2
          4. Thursday
             a. Time 1
             b. Time 2
          5. Friday
             a. Time 1
b. Time 2

6. Saturday
   a. Time 1
   b. Time 2

7. Sunday
   a. Time 1
   b. Time 2

After completing the questions, a new screen will appear with the following: “Thank you for completing this background information. We will review your information and contact you soon regarding eligibility to schedule participation in a focus group. In the meantime, if you have questions, you can reach us at emily.auerbach@uconn.edu.”

b. No
   (If no) Participant will be exited from the survey and directed to a “thank you” message.
APPENDIX A.2

Phase Two Demographic Survey

Inclusion Criteria:
1. Are you the primary caregiver of an individual with a developmental disability?
   a. Yes
   (if Yes) Are you the sole provider of care for this child?
      Yes
      No
   (if No) Who shares caregiving responsibilities with you?
      Spouse/Partner
      Sibling
      Parent
      Other: text box
   b. No

2. Is the individual you are caring for currently between 3 and 21 years of age?
   a. Yes
   b. No

3. Which of the following disability diagnoses have been given to the child you care for?
   a. Developmental Delay
   b. Autism Spectrum Disorder
   c. Intellectual Disability (including Down Syndrome)
   d. Attention Deficit/Hyperactivity Disorder
   e. Learning Disability
   f. Cerebral Palsy
   g. Blindness
   h. Stuttering/Stammering
   i. Seizures
   j. Other: text box

4. Do you have a Facebook account?
   a. Yes
      (if Yes) Do you log in to your Facebook account at least two times per week?
         Yes
         No
   b. No

Note: Questions are programmed so that a NO answer to 1 or 2 will not continue questions, as a person has not met inclusion criteria. If no box is checked in response to question 3, the person also has not met inclusion criteria as it is unclear as to whether developmental disability is present/understood. A NO answer to question 4 will also discontinue questions, as a Facebook account is required to participate in the intervention.

If an inclusion criterion has not been met, a screen will be provided indicating: “We appreciate your interest. At this time, you are not eligible to participate in this research study. If you have any questions, you can contact the researcher at emily.auerbach@uconn.edu. Thank you.”
If all inclusion criteria are met, the person will be directed to a new screen containing an information sheet for participation in the online demographic survey and an option to either continue on or exit the survey. If a person chooses to exit, then a “thank you” screen will appear. If a person chooses to continue on, they will proceed through the next questions.

Caregiver Demographics:

5. What is your relationship to the child with a developmental disability that you care for?
   a. Parent
   b. Grandparent
   c. Guardian
   d. Other: text box

6. What is your age?
   a. 18-24 years old
   b. 25-34 years old
   c. 35-44 years old
   d. 45-54 years old
   e. 55-64 years old
   f. 65-74 years old
   g. 75 or older

7. What is your gender/gender identity?
   a. Male
   b. Female
   c. Other: text box – non-required field
   d. Prefer not to say

8. What category best describes your ethnicity?
   a. Hispanic, Latino, or Spanish origin
      i. Mexican, Mexican American, Chicano
      ii. Puerto Rican
      iii. Cuban
      iv. Other: text box
   b. Not of Hispanic, Latino, or Spanish origin
   c. Prefer not to say

9. What category/categories best describes your race?
   a. American Indian/Alaska Native
   b. Asian
   c. Black or African American
   d. Native Hawaiian/Other Pacific Islander
   e. White/Caucasian
   f. Other: text box
   g. Prefer not to say

10. What is your level of education?
    a. Less than a high school diploma
    b. High school degree or equivalent (e.g., GED)
    c. Some college, no degree
    d. Associate degree (e.g., AA, AS)
    e. Bachelor’s degree (e.g., BA, BS)
11. What is your annual household income?
   a. Less than $20,000
   b. $20,000 to $34,999
   c. $35,000 to $49,999
   d. $50,000 to $74,999
   e. $75,000 to $99,999
   f. $100,000 to $149,999
   g. Over $150,000

12. What is your marital status?
   a. Single (never married)
   b. Married, or in a domestic partnership
   c. Widowed
   d. Divorced
   e. Separated
   f. Other: text box

13. What is your current employment status?
   a. Employed full time (40 or more hours per week)
   b. Employed part time (up to 39 hours per week)
   c. Unemployed and currently looking for work
   d. Unemployed and not currently looking for work
   e. Student
   f. Retired
   g. Homemaker
   h. Self-employed
   i. Unable to work

Child Demographics:
14. What is the current age of the child with a developmental disability that you care for?
   a. Dropdown ranging from 3y 0m to 21y 11m

15. What is the gender of the child with a developmental disability that you care for?
   a. Male
   b. Female
   c. Other

16. At what age did the child you care for first receive diagnosis of a developmental disability?
   a. Dropdown ranging from 0 to 21

17. Does the child with a developmental disability that you care for regularly attend daycare or school?
   a. Yes
      (If Yes) Approximately how many hours per weekday is your child at daycare or in school?
      Dropdown ranging from “Less than 1 hour” to “10 or more hours”
      Does your child have an Individualized Education Program (IEP)?
Does your child have a 504 Plan?
   Yes
   No

b. No

**Intervention Interest:**
1. Would you be interested in participating in a Facebook group intervention that seeks to support health-promotion and self-care for caregivers of children with developmental disabilities?
   a. Yes
      i. Are you a UConn employee, staff member, or student?
         1. Yes
            a. If yes, a message will display that states: “It is possible that you may encounter other UConn employees or students during your participation in the Facebook group intervention. If you are comfortable with this and wish to continue, select “Yes.” If you no longer wish to proceed, please select “No.””
               i. Yes ➔ Proceed to next question.
               ii. No ➔ Participant will be exited from the survey and directed to a “thank you” message.
         2. No
            (If no) Proceed to next question.
      ii. What is your name?
      iii. What is your email address?

After completing the questions, a new screen will appear with the following: “Thank you for completing this background information. We will review your information and contact you soon regarding eligibility to participate in this study. In the meantime, if you have questions, you can reach us at emily.auerbach@uconn.edu.”

b. No
(If no) Participant will be exited from the survey and directed to a “thank you” message.
APPENDIX B

Focus Group Interview Protocol

Introduction: Thank you for taking the time to share your experience being the primary caregiver of a child with a developmental disability (DD) who participates in an existing Facebook group. Our focus group is expected to take approximately 1 hour. I’ll be asking questions related to your current experiences with stress, health behaviors, and social support that are designed to guide the development of a Facebook group intervention for caregivers such as yourselves. Do you have any questions before we get started?

Focus Area 1. Stress

1. What responsibilities or activities associated with caring for a child with a developmental disability are the greatest source(s) of stress?
   a. Prompt - Describe the typical stressors you experience on a daily basis.

2. How does this stress impact other areas of your life?
   a. Prompt – For example, work, relationships, leisure activities, diet, exercise, sleep.

Focus Area 2. Health-Promoting Self-Care

3. What self-care behaviors do you currently engage in?
   a. Prompt – For example, going to the doctor/therapy/appointments with professionals, eating a healthy diet, getting 7-9 hours of sleep, regular exercise, going to church/temple/place of worship/prayer, participating in Facebook or in-person support group.

4. In an ideal world, what self-care behaviors would you most like to engage in given the necessary resources and support?
   a. Prompt – For example, going to the doctor/therapy/appointments with professionals, eating a healthy diet, getting 7-9 hours of sleep, regular exercise, going to church/temple/place of worship/prayer, participating in Facebook or in-person support group.

Focus Area 3. Social Support

5. Who do you consider when you think of your support network?
   a. Prompt – if Facebook group or online network does not come up, ask why or whether these individuals are part of their network.

6. What types of support do these individuals provide that is most helpful?
   a. Prompt – For example, emotional support, information or resources, respite.

7. In an ideal world, what types of support would you like more of?
   a. Prompt – For example, emotional support, information or resources, respite.

Conclusion: Thank you for taking the time to participate in this focus group. Your thoughts and feedback are greatly appreciated!
APPENDIX C

Fidelity Measure (adapted from Pagoto et al., 2016)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What percentage of participants actually joined the Facebook group?</td>
</tr>
<tr>
<td>2.</td>
<td>What percentage of planned posts were actually posted?</td>
</tr>
<tr>
<td>3.</td>
<td>How many views did each post get?</td>
</tr>
<tr>
<td>4.</td>
<td>On average, what percentage of posts did each participant view?</td>
</tr>
<tr>
<td>5.</td>
<td>How often did the interventionist log in?</td>
</tr>
<tr>
<td>6.</td>
<td>What percentage of participant posts/comments did the interventionist “like”?</td>
</tr>
<tr>
<td>7.</td>
<td>What percentage of participant posts/comments did the interventionist reply to or comment on?</td>
</tr>
</tbody>
</table>
APPENDIX D

Modified Usage Rating Profile – Intervention (Revised; adapted from Chafouleas et al., 2011)

Directions: Circle the number that best reflects your agreement with the statement using the scale provided below.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The Facebook support group was an effective choice for addressing a variety of problems for caregivers of children with developmental disabilities.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>2. I was able to allocate my time to participate in the Facebook support group.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>3. I understood how to use the Facebook support group.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>4. I am knowledgeable about the Facebook support group procedures.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>5. The Facebook support group is a fair way to handle caregivers’ health promotion challenges.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>6. The total time required to participate in the Facebook support group was manageable.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>7. I would not be interested in participating in the Facebook support group again.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>8. I would have positive attitudes about participating in the Facebook support group again.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>9. The Facebook support group is a good way to handle caregivers’ health promotion challenges.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>10. Preparation of resources (e.g., materials, food, supplies) needed for the Facebook support group was minimal.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>11. Material resources needed for the Facebook support group were reasonable.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>12. I would participate in the Facebook support group again with a good deal of enthusiasm.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>13. The Facebook support group procedures were too complex to carry out accurately.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>14. The Facebook support group was not disruptive to my family.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>15. I would be committed to carrying out the Facebook support group procedures on my own.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>16. The Facebook support group procedures easily fit in with my daily responsibilities.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>17. I understood the procedures of the Facebook support group.</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>18. The amount of time required for completing the Facebook support group procedures was reasonable.</td>
<td>1 2 3 4 5 6</td>
</tr>
</tbody>
</table>
## Intervention Plan

<table>
<thead>
<tr>
<th>Week</th>
<th>Topics Covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Self-care education: preparing for self-care through increasing health literacy; setting realistic short-term goals</td>
</tr>
<tr>
<td>2</td>
<td>Identifying current strengths, identifying areas for improvement; introduction to self-care skills</td>
</tr>
<tr>
<td>3</td>
<td>Self-care for physical health: skills related to exercise, nutrition, and sleep</td>
</tr>
<tr>
<td>4</td>
<td>Stress management and health; introduction to stress, depression, and anxiety</td>
</tr>
<tr>
<td>5</td>
<td>Mindfulness; relaxation techniques (progressive muscle relaxation, guided imagery, deep breathing); enhancing coping skills</td>
</tr>
<tr>
<td>6</td>
<td>The importance of a support network; building and repairing relationships; asking for help; using your support network to help achieve your goals</td>
</tr>
<tr>
<td>7</td>
<td>Work and play: goals and skills to maintain a balance between what you HAVE to do and what you WANT to do</td>
</tr>
<tr>
<td>8</td>
<td>Identify long-term goals and objectives; planning for continued support and progress</td>
</tr>
</tbody>
</table>

APPENDIX E.2

Week 1 Posts and Content

1. Welcome to Week 1 of our self-care intervention! This week, I’ll be posting much more at one time than will be typical throughout the following weeks – going forward, I’ll post resources throughout the week so you aren’t bombarded with a ton of information at one time! First, I’m going to share some more details about what to expect over the course of the intervention. Then, we’re going to talk about self-care and set some self-care goals! [Intervention Intro Infographic]

2. Self-care is a hot topic right now, but what does it really mean? For the purpose of this intervention, we’re going to use the definition of self-care in the center of this picture. Regardless, the concept of self-care can, ironically, be overwhelming because it’s so broad! The six areas in the picture are designed to break down all the possible ways we can engage in self-care into more specific categories. This is so that we can identify your personal highest priority areas to give you the biggest bang for your self-care buck! What do these 6 areas mean to you? [Self-Care graphic]

3. These are the general definitions my research team came up with for the 6 broad self-care areas. These are definitely not all-encompassing, but serve as a starting point for you to think about your successes and challenges with self-care! In talking to parents/caregivers, some important areas they felt were not represented in this include finances/money and spirituality. Do you agree, or have other areas in your life that you feel are not represented here? [Self-care areas definitions]

4. The bulk of the work for the intervention happens right now! There are two attachments to this post. The first includes instructions for how to a) identify your top priority for self-care; b) set an ideal goal for this area; and c) smaller incremental, achievable sub-goals to help you work up to your ideal goal. The second includes a template for typing/writing out your “Progress Scale.” This is where you’ll put the goals you create using the first attachment. You will use this throughout the intervention to complete the weekly surveys. You can choose to keep it to yourself, share it with me, or share it with the group – it is up to you! [Setting Goals] [Progress Scale Template]
APPENDIX E.3

**Week 2 Posts and Content**

1. Welcome to Week 2! You successfully made it through the first week, which is something to celebrate! This week, we’re going to talk more about overall self-care. I hope this helps you continue to work towards your first self-care goal. Keep up the great, supportive conversations!

2. What action(s) are you going to take this week to make progress toward your goal? Here is the link to complete your Week 2 survey: https://uconn.co1.qualtrics.com/jfe/form/SV_0jrtBNynNlUDeKh

3. What are your barriers to self-care? Identifying these can help us troubleshoot challenges that might come up throughout the intervention! https://drive.google.com/file/d/1Mdw5hlcpyMjk88-tLrvX40pfalbzyx2I/view?usp=sharing

4. What are your self-care strengths? We all have strengths, and it is important to recognize and celebrate them! Can you use any of your strengths to help combat the barriers you identified? https://drive.google.com/file/d/17EBNt-BszvTaVTXbLmzN1NGFkHUb-Oc/view?usp=sharing

5. Here is a list of free or low-cost mobile applications to support your self-care goals! Do you use any of these? Are there other apps you use for self-care? https://create.piktochart.com/output/41593466-self-care-apps
APPENDIX E.4

Week 3 Posts and Content

1. Welcome to Week 3! You’re already on your third week, and that much closer to developing new self-care habits! This week, we’re going to address self-care for physical health. If you have a goal related to food/eating, exercise/play, sleep, etc., this week will provide you with some information and resources most relevant to your goal. If you do not have a goal in this area, please share any successes/challenges you do experience and support your fellow parents/caregivers who are working to improve their self-care in this area!

2. What action(s) are you going to take this week to make progress toward your goal? Keep up the great work - here is the link to complete your Week 3 survey: https://uconn.co1.qualtrics.com/jfe/form/SV_9ZzhBhGi5r5mggR

3. Does anyone count calories? Have you found it to be helpful in supporting a healthy lifestyle? https://create.piktochart.com/output/39751278-week-1-health-literacy-2

4. Not sure where to get started with nutrition or eating healthy? The USDA has a tool called MyPlate that can help! https://www.choosemyplate.gov/eathealthy/start-simple-myplate

5. Are you working to live a “heart healthy” lifestyle? https://www.cdc.gov/chronicdisease/resources/infographic/hearthealth.htm


APPENDIX E.5

Week 4 Posts and Content

1. Welcome to Week 4! You’ve almost made it to the halfway point, so give yourselves a big pat on the back! This week, we’re going to address self-care for mental/emotional health. If you have a goal related to reducing stress, depression, anxiety, etc., this week will provide you with some information and resources most relevant to your goal. If you do not have a goal in this area, please share any successes/challenges you do experience and support your fellow parents/caregivers who are working to improve their self-care in this area!

2. What action(s) are you going to take this week to make progress toward your goal? Keep up the great work - here is the link to complete your Week 4 survey: https://uconn.co1.qualtrics.com/jfe/form/SV_bsaSseGlrhmKTe1


5. Here are some strategies that you can use to reduce symptoms of stress and anxiety. Do you use any of these or have other strategies you like to use? https://adaa.org/tips-manage-anxiety-and-stress

6. Cognitive Behavioral Therapy, or CBT, is an effective intervention/treatment for anxiety, depression, and other psychological disorders. https://adaa.org/sites/default/files/what-is-cbt_0_0.png

7. If you are experiencing symptoms of depression, do your loved ones know how to talk to you? https://adaa.org/learn-from-us/from-the-experts/blog-posts/consumer/how-do-you-talk-your-loved-one-suffering
APPENDIX E.6

Week 5 Posts and Content

1. Welcome to Week 5! You’ve officially made it halfway through the intervention! This week, we’re going to continue the conversation about stress by talking about mindfulness, relaxation, and coping strategies. Please share any successes/challenges you experience in this area.

2. What action(s) are you going to take this week to make progress toward your goal? Keep up the great work - here is the link to complete your Week 5 survey: https://uconn.co1.qualtrics.com/jfe/form/SV_8AiTygNabQPseFv

3. Whether you’re familiar with mindfulness and use it, have heard the term but don’t know what it means, or have never heard of the concept, this website provides information, resources, and videos about ways all of you can incorporate mindfulness into your life! https://www.mindful.org/meditation/mindfulness-getting-started/

4. If mindfulness isn’t for you, or if you want additional strategies to help with relaxation and stress reduction, try one of the strategies listed on this website! https://www.verywellmind.com/popular-relaxation-techniques-2584192

5. Emotion-focused coping strategies can be effective for reducing stress in situations where the stressor can’t be eliminated, such as parenting stress. Have you used these strategies before? https://www.verywellmind.com/emotion-focused-coping-for-stress-relief-3145107

6. Rutgers University Robert Wood Johnson Medical School published an alphabet of stress management and coping skills that can serve as a menu of actions you can take to better cope with stress! http://rwjms.rutgers.edu/departments_institutes/cf_center/documents/Alphabet-of-Coping-Skills-Interventions.pdf

7. Here is another great article with tips for managing stress, but specifically for parents of kids with disabilities: https://www.verywellfamily.com/parent-disability-stress-tips-2162645
APPENDIX E.7

Week 6 Posts and Content

1. Welcome to Week 6! You are more than halfway through the intervention - woohoo! This week, we’re going to talk about self-care for relationships and social support. If you have a goal related to making new adult connections, reducing conflict in your marriage/partnership, spending time with loved ones, etc., this week will provide you with some information and resources most relevant to your goal. If you do not have a goal in this area, please share any successes/challenges you do experience and support your fellow parents/caregivers who are working to improve their self-care in this area!

2. What action(s) are you going to take this week to make progress toward your goal? Keep up the great work - here is the link to complete your Week 6 survey: https://uconn.co1.qualtrics.com/jfe/form/SV_blunZJxRDqJk8TP


4. Why is social support so important and how can it benefit you? https://www.apa.org/helpcenter/emotional-support

5. Asking for help when you need it is important, but challenging because it requires us to be vulnerable. Brene Brown’s famous TED Talk sheds some light on the importance of connection and vulnerability (integrating humor, which I always appreciate!). Do you struggle to let yourself be vulnerable and/or ask for help? https://www.ted.com/talks/brene_brown_on_vulnerability

6. The University of Buffalo School of Social Work has a self-care kit for the students in their program, with guidance on developing a support system. One concept that is applicable to all of us is referred to as “Identifying your Breathe Supports,” or the people who can help you identify when you are distressed (sometimes even before you notice!). Do you have “breathe” supports in your network? http://socialwork.buffalo.edu/content/dam/socialwork/home/self-care-kit/identifying-your-breathe-supports-reiser.pdf
1. Welcome to Week 7! We are nearing the end of our time together, so let’s make the most of it! This week, I will provide you with some information and resources about work-life balance, play, and time management. Please share any successes/challenges you do experience and support your fellow parents/caregivers who are working to improve their self-care in this area!

2. What action(s) are you going to take this week to make progress toward your goal? Keep up the great work - here is the link to complete your Week 7 survey: https://uconn.co1.qualtrics.com/jfe/form/SV_7TIDA9t2Fr7pJvn

3. If the term “work-life balance” seems totally unachievable, here are some tips to help reframe what it means. What would it mean to you to have a work-life balance? https://www.businessnewsdaily.com/5244-improve-work-life-balance-today.html

4. Here is a great article with information about why “play” is important for adults, what it might look like, and how to make time for it. How do you incorporate play into your life? https://www.brighterpathcounseling.com/importance-of-play-for-adults/

5. If you’re looking for more ideas for how to increase play time in your life, and how to involve your family, here is another great article: https://www.helpguide.org/articles/mental-health/benefits-of-play-for-adults.htm

6. Are you struggling to manage your time amidst everything you have to get done for your kids, family, and yourself? Here are some helpful tips from Amica (not an ad for insurance, just a great article!): https://www.amicalifelessons.com/checklist/time-management-tips-for-family-caregivers/

7. Here are some more time management tips from a mom of two kiddos with special needs. Have you used or tried any of these? https://moneysavingmom.com/time-management-tips-for-parents-with-special-needs-kids/
Week 8 Posts and Content

1. Welcome to the final week of the intervention! Since self-care shouldn’t end when the intervention does, this week, we’re going to talk about how to plan for long-term success. What action(s) are you going to take this week to continue to make progress toward your goal? Here is the link to complete your Week 8 survey: https://uconn.co1.qualtrics.com/jfe/form/SV_9BH5FVm1DKnQrLvL.

2. Here is a helpful resource for setting and achieving goals, which you can use to either build upon the work you’ve done in this group or to set new goals in the future: https://www.mindtools.com/page6.html

3. If you’re interested in continuing to work on health-related goals, here is a helpful website with tools to help you set and achieve mental, emotional, and physical health goals: https://www.achieve-goal-setting-success.com/health-goals.html

4. An important component to achieving goals is an accountability system. Here is some guidance on how to leverage your accountability system: https://medium.com/the-mission/the-accountability-effect-a-simple-way-to-achieve-your-goals-and-boost-your-performance-8a07c76ef53a

5. This article shares some great examples of how others can support you in achieving your goals and vice versa: https://hbr.org/2016/01/you-cant-achieve-your-goals-without-the-right-support

6. The Family Caregiver Alliance website has a number of helpful resources for supporting yourself and the person for whom you are providing care. All of the content is not necessarily geared towards parents of children and adolescents, but the National Center on Caregiving has information about supports for caregivers in all 50 states: https://www.caregiver.org/national-center-caregiving

7. Thank you all so much for taking the time to participate in my dissertation study. I have truly enjoyed learning from all of you and hope that this group has been a positive experience! In the next few days, I will send you an email with a link to an end-of-study survey. Once you complete this, I will follow up about the gift card incentive. Thank you again!
University of Connecticut

Caregivers of Children with Developmental Disabilities Wanted for a Research Study

*Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities*

Caregivers of children with developmental disabilities can experience unique demands on their lives. We are interested in understanding the successes and challenges that caregivers have in self-care that promotes personal health and well-being.

We seek caregivers of children with developmental disabilities (ages 3 to 21 years) to learn about their experiences as a caregiver, and particularly about their personal self-care behaviors. The information will be used to inform development of supports to assist health-promoting self-care behaviors.

Participants will receive a $10 gift card for completion of a focus group.

To learn more about this study, please email emily.auerbach@uconn.edu

*Note. The Project Director is Dr. Sandra M. Chafouleas, Professor in the Department of Educational Psychology at UConn.*
APPENDIX G.1

Information Sheet for Participation in a Research Study

**Principal Investigator:** Sandra M. Chafouleas

**Student Researcher:** Emily R. Auerbach

**Study Title:** Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

**Introduction**

You are invited to participate in a research study that is exploring the experience of primary caregivers of children with developmental disabilities who participate in Facebook groups. We are particularly interested in understanding the successes and challenges that you experience to engaging in self-care strategies that promote your health and well-being.

**Why is this study being done?**

Information from this exploratory study will be used to inform the development of a Facebook group intervention that may assist caregivers with self-care strategies that promote health and well-being.

**What are the study procedures? What will I be asked to do?**

The study first involves completing a series of brief questions about you and the child with a developmental disability that you care for. Questions provide background information, such as age, gender, employment, disability status, etc… Your answers will be used to determine eligibility to proceed to the interview portion of the study. We will review the information to make sure that you meet the criteria to be included, and to make sure that our total sample includes a diverse range of caregivers of a child with a developmental disability. You will be notified if you are invited to proceed to the next stage of the research study, which involves a focus group with other caregivers, facilitated by a member of the research team.

If you proceed to the focus group portion of the research study, we will review the study procedures with you and ask that you provide written consent to continue. During the focus group, you will be asked to describe aspects of your experience as a caregiver for a child with a developmental disability, self-care behaviors you engage in to support your health and well-being, and your network of support. The focus group will take between 60 and 90 minutes and will be scheduled at your convenience to take place virtually using Cisco WebEx. The focus
group will be audio-taped and transcribed by the research team. Following completion of the focus group, you may be contacted again within a 3-year period regarding opportunities to participate in a follow-up study.

What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the questions, which should take no longer than 10 minutes.

What are the benefits of the study?

By participating in this study, you will contribute to the knowledge about the experiences of caregivers of children with developmental disabilities. It is expected that your responses will help guide researchers in developing supports for caregivers to benefit their self-care.

Will I receive payment for participation? Are there costs to participate?

There are no costs and you will not be paid to participate in this screening. If you proceed through completion of the focus group portion of the study, you will receive a $10 gift card in appreciation.

How will my personal information be protected?

The following procedures will be used to protect the confidentiality of your screening data. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. If you have not been selected to continue to the focus group phase, all records to your information will be destroyed after 3 years. If you continue to the focus group phase, your research records will be labeled with a code. The code will be derived from a number that reflects how many people have enrolled in the study. A master key that links names and codes will be maintained in a separate and secure location. The master key and audiotapes will be destroyed after 3 years.

Data that will be shared with others will be coded as described above to help protect your identity. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

We will do our best to protect the confidentiality of the information we gather from you but we cannot guarantee 100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

You should also know that the UConn Institutional Review Board (IRB) and Research Compliance Services may inspect study records as part of its auditing program, but these reviews will only focus
on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

**Can I stop being in the study and what are my rights?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. In addition, you do not have to answer any question that you do not want to.

**Whom do I contact if I have questions about the study?**

Take as long as you like before you make a decision. We will be happy to answer any questions you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator, Dr. Sandra Chafouleas, at 860-486-6868, or the student investigator, Emily Auerbach, at emily.auerbach@uconn.edu. If you have any questions concerning your rights as a research subject, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.
APPENDIX G.2

Consent Form for Participation in a Research Study

Principal Investigator: Sandra M. Chafouleas
Student Researcher: Emily R. Auerbach
Study Title: Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

Overview of the Research

You are being asked to provide consent to participate in a research study. Participation is voluntary. You can say yes or no. If you say yes now you can still change your mind later. Some key points to consider are summarized in this overview, but you should consider all of the information in this document carefully before making your decision. This research is being done to determine how best to proceed with developing an intervention for caregivers of children with developmental disabilities. Participation will involve approximately 1 and a half hours of your time over 1 day. You will be asked to be in a focus group about the successes and challenges you experience with your self-care, health, and well-being with 7 other caregivers of children with developmental disabilities and 1 member of the research team. We believe there are no known risks to participating in the study aside from the time it takes to complete the focus group. This research may result in information that leads to improved understanding of how best to support caregivers of children with developmental disabilities. A more detailed description of this research follows.

Introduction

You are invited to participate in a research study that is exploring the experience of primary caregivers of children with developmental disabilities who participate in Facebook groups. We are particularly interested in understanding the successes and challenges that you experience to engaging in self-care strategies that promote your health and well-being.

Why is this study being done?

Information from this exploratory study will be used to develop a Facebook group intervention that may assist caregivers with self-care strategies that facilitate their health and well-being.

What are the study procedures? What will I be asked to do?
If you agree to take part in this study, you will be asked to participate in a focus group with 7 other caregivers of children with developmental disabilities, facilitated by a member of the research team. During the focus group, you will be asked to describe aspects of your experience as a caregiver for a child with a developmental disability, self-care behaviors you engage in to support your health and well-being, and your network of support. The focus group will take between 60 and 90 minutes and will be scheduled at your convenience to take place virtually using Cisco WebEx, a secure online video conferencing platform. The focus group will be audiotaped using Cisco WebEx and transcribed by the research team. Following completion of the focus group, you may be contacted again within a 3-year period regarding opportunities to participate in a follow-up study using the contact information you provided in the initial online survey.

**What are the risks or inconveniences of the study?**

There is an inherent risk of participating in a focus group in that members of the group might not keep what is said during the group confidential. However, at the start of the focus group, all group members will be reminded to keep information discussed during the focus group confidential. In addition, a possible inconvenience may be the time it takes to complete the focus group, which will take no longer than 90 minutes.

**What are the benefits of the study?**

You may not directly benefit from this research; however, we hope that your participation in the study will help researchers develop an intervention for caregivers of children with developmental disabilities to benefit their self-care. In addition, you will contribute to the knowledge about the experiences of caregivers of children with developmental disabilities.

**Will I receive payment for participation? Are there costs to participate?**

There are no costs to participate in this study. If you proceed through completion of the focus group portion of the study, you will receive a $10 gift card in appreciation.

**How will my personal information be protected?**

The following procedures will be used to protect the confidentiality of your screening data. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. If you have not been selected to continue to the focus group phase, all records to your information will be destroyed after 3 years. If you continue to the focus group phase, your research records will be labeled with a code. The code will be derived from a number that reflects how many people have enrolled in the study. A master key that links names and codes will be maintained in a separate and secure location. The master key and audiotapes will be destroyed after 3 years.
Data that will be shared with others will be coded as described above to help protect your identity. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

We will do our best to protect the confidentiality of the information we gather from you but we cannot guarantee 100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties. If, during the course of this research study, a UConn employee suspects that a minor (under the age of 18) has been abused, neglected, or placed at imminent risk of serious harm, it will be reported directly to the Department of Children and Families (DCF) or a law enforcement agency.

You should also know that the UConn Institutional Review Board (IRB) and Research Compliance Services may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. During the focus group, you do not have to answer any question that you do not want to answer.

Whom do I contact if I have questions about the study?

Take as long as you like before you make a decision. We will be happy to answer any questions you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator, Dr. Sandra Chafouleas, at 860-486-6868, or the student investigator, Emily Auerbach, at emily.auerbach@uconn.edu. If you have any questions concerning your rights as a research subject, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

Documentation of Consent:
I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible risks and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I have received a copy of this consent form.

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<th>Participant Signature:</th>
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University of Connecticut

Caregivers of Children with Developmental Disabilities Wanted for a Research Study

Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

Caregivers of children with developmental disabilities can experience unique demands on their lives. We are interested in supporting the challenges that many caregivers have in self-care that promotes personal health and well-being.

We seek primary caregivers of children with developmental disabilities (ages 3 to 21 years) to participate in a Facebook group intervention designed to provide self-care strategies and group support in order to reduce stress and improve health and well-being.

Participants will receive a $50 gift card for completion of the study procedures.

To learn more about participating in this study, please visit https://sites.google.com/uconn.edu/caregiverdissertationstudy/

Email emily.auerbach@uconn.edu with any questions.

Note. The Project Director is Dr. Sandra M. Chafouleas, Professor in the Department of Educational Psychology at UConn.

UConn IRB PROTOCOL H19-111 APPROVED August 23, 2019
APPENDIX I.1
Information Sheet for Participation in a Research Study

Principal Investigator: Sandra M. Chafouleas
Student Researcher: Emily R. Auerbach
Study Title: Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

Overview of the Research

You are being asked to provide consent to participate in a research study. Participation is voluntary. You can say yes or no. If you say yes now you can still change your mind later. Some key points to consider are summarized in this overview, but you should consider all of the information in this document carefully before making your decision.

This research is being done to better understand if a self-care intervention delivered through a Facebook group will impact the stress, health, and well-being of caregivers of children with developmental disabilities. Participation will involve completion of a demographic survey that includes questions about you and the child with a disability that you care for. This is a one-time survey that will take between 10-15 minutes to complete.

We believe there are no known risks to participating in the study aside from the time it takes to complete the survey. Risks are described in more detail later in this form. There are no known benefits to participating in this study, but your response may result in an improved understanding of how best to support caregivers of children with developmental disabilities.

A more detailed description of this research follows.

Introduction

You are invited to participate in a research study to examine effective strategies for supporting the health and well-being of caregivers of children with developmental disabilities. You are being asked to participate because you are at least 18 years of age; are the primary caregiver of a child aged 3-21 with a developmental disability; use Facebook; and can read and write in English.

Why is this study being done?
The purpose of this research study is to pilot a Facebook group intervention designed to assist caregivers with self-care strategies that facilitate their health and well-being. This study aims to remove barriers such as time, transportation, and child care to accessing both the intervention and social support.

What are the study procedures? What will I be asked to do?

The study first involves completing a series of brief questions about you and the child with a developmental disability that you care for. Questions provide background information, such as age, gender, employment, disability status, etc. Your answers will be used to determine eligibility to proceed to the interview portion of the study. We will review the information to make sure that you meet the criteria to be included, and to make sure that our total sample includes a diverse range of caregivers of a child with a developmental disability. You will be notified if you are invited to proceed to the next stage of the research study, which involves a Facebook group intervention with other caregivers, facilitated by a member of the research team.

If you proceed to the intervention portion of the study, you will be asked to complete two surveys about your stress, health, and well-being; join a “secret” Facebook group with up to 50 other caregivers of children with developmental disabilities and members of the research team; complete a weekly rating (e.g., on a scale from 1 to 5) of your self-care; and read and respond to posts in the Facebook group. Participation in the intervention will involve between 1 and 5 hours of your time per week over 8 weeks.

What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the questions, which should take no longer than 15 minutes.

What are the benefits of the study?

By participating in this study, you will contribute to the knowledge about the experiences of caregivers of children with developmental disabilities. It is expected that your responses will help guide researchers in developing supports for caregivers to benefit their self-care.

Will I receive payment for participation? Are there costs to participate?

There are no costs and you will not be paid to participate in this screening. If you proceed through completion of the intervention portion of the study, you will receive a $50 gift card in appreciation.

How will my personal information be protected?

The following procedures will be used to protect the confidentiality of your screening data. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to
prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. If you have not been selected to continue to the focus group phase, all records to your information will be destroyed after 3 years. If you continue to the intervention phase, your research records will be labeled with a code. The code will be derived from a number that reflects how many people have enrolled in the study. A master key that links names and codes will be maintained in a separate and secure location. The master key and audiotapes will be destroyed after 3 years.

Data that will be shared with others will be coded as described above to help protect your identity. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

We will do our best to protect the confidentiality of the information we gather from you but we cannot guarantee 100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

You should also know that the UConn Institutional Review Board (IRB) and Research Compliance Services may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. In addition, you do not have to answer any question that you do not want to.

Whom do I contact if I have questions about the study?

Take as long as you like before you make a decision. We will be happy to answer any questions you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator, Dr. Sandra Chafouleas, at 860-486-6868, or the student investigator, Emily Auerbach, at emily.auerbach@uconn.edu. If you have any questions concerning your rights as a research subject, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.
APPENDIX I.2

Consent Form for Participation in a Research Study

Principal Investigator: Sandra M. Chafouleas  
Student Researcher: Emily R. Auerbach  
Study Title: Development of a Facebook Group Intervention to Increase Health-Promoting Self-Care Among Primary Caregivers of Children with Developmental Disabilities

Overview of the Research

You are being asked to provide consent to participate in a research study. Participation is voluntary. You can say yes or no. If you say yes now you can still change your mind later. Some key points to consider are summarized in this overview, but you should consider all of the information in this document carefully before making your decision.

This research is being done to better understand if a self-care intervention delivered through a Facebook group will impact the stress, health, and well-being of caregivers of children with developmental disabilities. Participation will involve between 1 and 5 hours of your time per week over the next 8 weeks. You will be asked to complete two surveys about your stress, health, and well-being; join a “secret” Facebook group with up to 50 other caregivers of children with developmental disabilities and members of the research team; complete a weekly rating (e.g., on a scale from 1 to 5) of your self-care; and read and respond to posts in the Facebook group.

The main risk or inconvenience of participating in the Facebook group intervention is the time it takes to complete the surveys and intervention activities. Some of the questions on the surveys or discussions in the Facebook group may also cause you to feel upset. In addition, there is an inherent risk of participating in a Facebook group intervention in that what is said in the group might not be kept confidential by other group members. Risks are described in more detail later in this form.

If the intervention is effective, you may experience an improvement in your stress level and/or health and well-being; but this is not guaranteed. This research may also result in an improved understanding of how best to support caregivers of children with developmental disabilities.

A more detailed description of this research follows.
Introduction

You are invited to participate in a research study to examine effective strategies for supporting the health and well-being of caregivers of children with developmental disabilities. You are being asked to participate because you are at least 18 years of age; are the primary caregiver of a child aged 3-21 with a developmental disability; use Facebook; and can read and write in English.

Why is this study being done?

The purpose of this research study is to pilot a Facebook group intervention designed to assist caregivers with self-care strategies that facilitate their health and well-being. This study aims to remove barriers such as time, transportation, and child care to accessing both the intervention and social support.

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will first be asked to complete a survey with questions about your current stress, health and well-being, and parenting, which will take approximately 10-15 minutes of your time. You will also be asked to join and participate in a “secret” Facebook group with up to 50 other caregivers of children with developmental disabilities and members of the research team for the next 8 weeks. As part of this group, the researcher will post prompts and activities, which you can complete independently/privately or via post in the group. Each activity should not take more than 60 minutes to complete. You will also complete a weekly rating (e.g., on a scale from 1 to 5) of your self-care progress, and read and “react” (e.g., like) to at least 1 post or comment in the Facebook group throughout each week. Participation will involve between 1 and 5 hours of your time per week outside of the time you typically spend using Facebook. You can post, comment, or reply as frequently as you would like; however, the more you post, the more time it will take. At the end of the 8-week period, you will be asked to complete a second survey with questions about your current stress, health and well-being, and parenting, along with your thoughts about the intervention, which will take approximately 15-20 minutes of your time. Following completion of the study, you will not be contacted again.

What are the risks or inconveniences of the study?

There is the possibility that a Facebook data breach could occur at some point during the course of the study. Please review the risks associated with participating in a Facebook group under the “How will my personal information be protected?” section. In addition, there is an inherent risk that what is said in the Facebook group might not be kept confidential by other group members. However, at the start of the intervention, all group members will be reminded to keep information discussed in the group confidential and a post will be “pinned”, or posted permanently, to the top of the group homepage that reminds all members about confidentiality. There is also the possibility that questions on the surveys or discussions in the Facebook group may cause you to become upset. In addition, a possible inconvenience may be the time it takes to complete the surveys, ratings, and study activities.
What are the benefits of the study?

You may not directly benefit from this research; however, we hope that your participation in the study may lead to an improvement in your stress level and/or health and well-being; but this is not guaranteed. This research may also result in an improved understanding of how best to support caregivers of children with developmental disabilities.

Will I receive payment for participation? Are there costs to participate?

There are no costs to participate in this study. If you proceed through completion of the intervention, including all required surveys and activities, you will receive a $50 gift card in appreciation.

How will my personal information be protected?

The following procedures will be used to protect the confidentiality of your data. The researchers will keep all study records (including any codes to your data) locked in a secure location. Research records will be labeled with a code. The code will be derived from a number (e.g. sequential 3-digit code that reflects how many people have enrolled in the study.) A master key that links names and codes will be maintained in a separate and secure location. The master key and any recordings will be destroyed after 3 years. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. Data that will be shared with others will be coded as described above to help protect your identity.

We will do our best to protect the confidentiality of the information we gather from you but we cannot guarantee 100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

As part of the intervention, you will be engaging in a “secret,” or private, Facebook group to interact with the researcher and fellow group members. Being involved in a “secret” Facebook group means that the public is unable to “see” the group and only the study team can invite users, which will include you, group leaders, and participants in the group. Any information transmitted via email, phone, or Facebook is only secure to the extent offered by the providers’ privacy/security policy; we encourage you to familiarize yourself with these policies. It is also important to keep in mind that anything you post on Facebook is technically governed by and can be used by Facebook; therefore, the study team cannot ensure complete confidentiality of all of your Facebook posts and information. Similarly, you may receive other notifications from Facebook or suggestions and requests about people you may know – this is controlled by Facebook and not the research team. Facebook terms and conditions may be updated periodically; therefore, we highly recommend that you go to https://www.facebook.com/legal/terms to check the latest statement of your rights and responsibilities related to Facebook use. The study team may also examine your Facebook group posts throughout the intervention for the frequency and nature of posts. These results may be presented, but if any data are presented the data will not be identifiable by name or other personal
information. Instead, the results will be presented anonymously and in aggregate (grouped) format. Given the limitations of technological security and privacy, we recommend that you be mindful of these limitations while sharing information and only share to the extent that you are comfortable.

You should also know that the UConn Institutional Review Board (IRB) and Research Compliance Services may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

**Can I stop being in the study and what are my rights?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time for any reason. There are no penalties or consequences of any kind if you decide that you do not want to participate. You do not have to answer any question that you do not want to answer. You will be notified of all significant new findings during the course of the study that may affect your willingness to continue.

**Whom do I contact if I have questions about the study?**

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this study or if you have a research-related problem, you may contact the principal investigator, Sandra M. Chafouleas (860-486-6868), or the student researcher, Emily Auerbach (860-989-4626). If you have any questions concerning your rights as a research participant, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

**Documentation of Consent:**

*I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible risks and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I have received a copy of this consent form.*

Participant Signature: __________________________ Print Name: __________________________ Date: __________________________

Signature of Person Obtaining Consent: __________________________ Print Name: __________________________ Date: __________________________