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School of Occupational Therapy

Developing, Implementing, and Evaluating a Respite Care Program: Impact on the Psychological Well-Being of Caregivers of Children with Disabilities

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A doctoral capstone project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

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A Doctoral Capstone Project Entitled

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Submitted to the School of Occupational Therapy at the University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

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Abstract

As the number of children being diagnosed with developmental disabilities continues to increase, so do the number of caregivers caring for those individuals. Due to the increased amount of care required by children with disabilities, caregivers often sacrifice their health and well-being to ensure these individuals' needs are being met (Brown et al., 1993; Earle & Heymann, 2011; Li et al., 2015). The inability of caregivers to tend to their own needs due to caregiving responsibilities creates increased caregiver stress. Caregiver stress predicts caregiver psychological well-being (Cramm & Nieboer, 2011, Dyches et al., 2016). As a result of caregivers experiencing increased stress, they are likely experiencing decreased psychological well-being (Cramm & Nieboer, 2011).

Respite care services provide caregivers temporary care for their child with a disability, with the primary goal being to provide the caregivers temporary emotional, physical, and mental relief (Cowen & Reed, 2002). Through engagement in respite care services, caregivers experience decreased stress and burden, providing for increased psychological well-being (Remedios et al., 2015).

The purpose of my doctoral capstone experience was to decrease caregiver burden and improve the psychological well-being of caregivers of children with mild to moderate disabilities, ages 5-18, through the development and implementation of a respite care program at Noblesville First United Methodist Church (NFUMC).

Developing, Implementing, and Evaluating a Respite Care Program: Impact on the Psychological Well-Being of Caregivers of Children with Disabilities

According to the Centers for Disease Control and Prevention (2019) and Zablotsky et al. (2019), approximately 1 in 6 children 3-17 years of age, or 17.8%, were diagnosed with a developmental disability between 2009 and 2017. This is a substantial increase in the overall rate of developmental disabilities, from 16.2% in 2009-2011 to 17.8% in 2015-2017 (Zablotsky et al., 2019). The increase in rate of developmental disabilities can be attributed to increases in the prevalence of attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), and intellectual disabilities (ID) (Zablotsky et al.). An additional 39 million children living in the U.S. have a disability (World Health Organization, 2018). These statistics are equivalent to approximately 15% of the world's population having a disability (World Health Organization, 2018). Of the one billion individuals impacted by a disability in today's society, between 110 million and 190 million individuals have a disability that results in difficulties functioning in daily activities (World Health Organization, 2018). Compared to previous years and decades, the number of individuals diagnosed with a disability is rising (World Health Organization, 2018). An increase in individuals diagnosed with disabilities indicates an increase in caregivers of individuals with disabilities.

A study conducted by Romley et al. (2017) concluded that caregivers of individuals with disabilities are family members, typically mothers, fathers, and siblings, who provide 49.7% of the health care to individuals with disabilities. They assist the individual with a disability to ensure their basic needs, such as feeding, dressing, hygiene, and toileting, are being met. They also provide a means for transportation and opportunities for socialization and leisure.

Caregiver burden has been analyzed in numerous studies as it relates to the elderly population. However, research related to caregiver burden is more limited when discussing the pediatric population. There are a variety of factors and predictors that relate to caregiver burden. A positive correlation exists between caregiver burden and caregiver psychological well-being and overall quality of life (Dyches et al., 2016). As a result of increased caregiver burden due to caring for a child with a disability, caregivers are at an increased risk for mental health diagnoses (Dyches et al., 2016).

Romley et al. (2017) also claimed that caregivers provide 1.5 billion hours of health care services each year, instead of receiving respite care services, to 5.6 million U.S. children with disabilities. Respite care services provide temporary care to the child with a disability, with the overall goal being to provide the caregiver of the child with temporary relief (Maayan et al., 2014). Caregivers that utilize respite care services experience decreased psychological distress (Mullins et al., 2002; Dyches et al., 2016). Respite services can be provided in a variety of settings, by a variety of individuals, and over differing durations of time. Whitmore (2016) offers the example that respite care services may be provided in a church with trained and/or untrained volunteers.

The purpose of this program was to decrease caregiver burden and improve the psychological well-being of caregivers of children with mild to moderate disabilities, ages 5-18, through the development and implementation of a respite care program at NFUMC. By being provided opportunities to engage in respite care services, one program goal was for caregivers to increase engagement in self-care tasks, including social participation, leisure exploration, and career pursuits, as well as their ability to attend to their health needs. Increased engagement in these activities could decrease caregivers' burden and improve their

psychological well-being. NFUMC could benefit from a respite care program because community outreach would provide for an expansion of their special needs ministry, specifically as it relates to the pediatric population. The greater Noblesville community would benefit from the development of a respite care program because they would be provided an additional resource and service to utilize. Caregivers in Noblesville and Hamilton County would have increased access to services that improve their well-being and overall quality of life.

Driving Theory and Conceptual Model

To guide program development, I chose to incorporate the Canadian Model of Occupational Performance (CMOP). The CMOP is an occupation-based model that assists occupational therapists in organizing and categorizing their thoughts around occupation, thinking about complex problems, and viewing clients through the lens of the profession (Cole & Tufano, 2008). The CMOP has the human spirit at its center, which serves as an individual's primary source of motivation, self-determination, and self-will (Cole & Tufano, 2008). The human spirit component of the CMOP was critical during the development of the respite program because I needed to be mindful of what caregivers of children with disabilities believe to be their purpose in life. As a future occupational therapist, I believe my purpose in life is to help individuals with disabilities and their families have an increased quality of life.

Many caregivers of children with disabilities have a similar human spirit, where they want to provide the best life for their child. In the CMOP, occupational performance is based on the interaction between the person, environment, and occupation (Cole & Tufano, 2008). Caregivers often become abundantly focused on the needs of their child, causing their

"occupation" component of the CMOP to be ignored (Cramm & Nieboer, 2011; Li et al., 2015). As a result of caregiving responsibilities associated with caring for a child with a disability, caregivers devote less time to personal health and self-care needs and decrease participation in leisure pursuits, relaxation, career exploration, and socialization with friends and family (Brown et al., 1993; Cramm & Nieboer, 2011; Earle & Heymann, 2011; Li et al., 2015). The "person" component of the CMOP is impacted, resulting in caregivers experiencing decreased physical and mental health, including stress, anxiety, worry, and fear about their child's future (Peer & Hillman, 2014).

Regarding the "environment" component of CMOP, the development of the respite program will provide caregivers of children with disabilities an opportunity for increased social participation. By participating in informal sources of support, such as community-based respite programs at a church, caregivers are provided social support and are surrounded by a network of other caregivers they can connect with to establish supportive relationships (Murphy et al., 2006). To fully comprehend the "environment" component of the CMOP, it was essential for me to obtain a greater sense of each family's culture, as well as the culture of the church.

I chose to incorporate the Psychodynamic frame of reference (FOR) during my DCE. The Psychodynamic (FOR) focuses on information, events, and material in an individual's unconscious mind being a significant influence on their behavior (Cole & Tufano, 2008). Function through this FOR is defined as being free of conflicts and fixations, having satisfied needs, appropriate emotional expression, and self-awareness (Cole & Tufano, 2008). The majority of caregivers of children with disabilities identify the surplus of caregiver responsibilities as being a primary cause of their stress, poor health, and decreased psychological well-being (Cramm & Nieboer, 2011). Caregivers often sacrifice their health and

psychological well-being to meet the extraordinary care needs of the individual with a disability (Brown et al., 1993; Earle & Heymann, 2011; Li et al., 2015). Caregivers typically have minimal social support and support services available to them, experience decreased leisure exploration, and have fewer career opportunities, all of which are unmet needs when viewing the scenario using the Psychodynamic FOR (Cramm & Nieboer, 2011; Li et al., 2015).

The inability of caregivers to attend to personal tasks due to caregiving responsibilities creates increased caregiver stress, which decreases caregiver psychological well-being (Cramm & Nieboer, 2011). As a result, caregivers are faced with emotional and psychological conflicts, including the fear that as their health and well-being continue to decrease as a result of caregiver stress, they will be unable to meet the long-term needs of their child with a disability (Murphy et al., 2006). Caregivers may also face conflict if they have to decide to place the individual with a disability outside of the home (Kelly & Hewson, 2000; McConnell, 2015).

Through participation in informal sources of support, such as a respite program, caregivers are provided with the social support they need (Murphy et al., 2006). Participation in the community-based respite program at NFUMC provides for an increase in the caregivers' social support, resulting in decreased stress and improved psychological well-being (Murphy et al., 2006). Caregivers may become free of conflict because their previously experienced anxiety and stress will be reiterated and brought to the forefront of their mind due to increased self-awareness.

Instead of caregivers sacrificing their health and well-being to meet the extraordinary care needs of the child with a disability, they are provided the opportunity to address and attend to their self-care and health as a result of these scheduled respite care services. In addition, through scheduled respite care services and informal sources of support, one program goal was

for caregivers to experience decreased caregiver burden, anxiety, and stress, providing for an improved psychological well-being. One way caregivers may experience this is through increased engagement in social participation, leisure exploration, and career pursuits.

Literature Review

Consequences of Poor Caregiver Health and Psychological Well-Being

Caregiver stress predicts caregiver psychological well-being (Cramm & Nieboer, 2011; Dyches, 2016). Caregiver burden may be defined as a caregiver's response to perceived stressors and negative appraisals as a result of them caring for an individual with a disability (Kim et al., 2012; Dyches et al., 2016). A child's inappropriate behavior, caregiving demands, and family circumstances, such as marital status are predictors of caregiver stress (Javalkar et al., 2017). Caregiver stress may also be predicted by multiple caregiver characteristics, such as education, employment, and caregiving duties, as well as the child's personality and behavior, demographic characteristics, and/or characteristics related to their disability (Javalkar et al., 2017).

Caregiver stress includes but is not limited to the caregiver attending to the individual with a disability's educational, emotional, medical, behavioral, and developmental needs, while simultaneously attempting to attend to their personal needs and meeting the demands of daily life (Cramm & Nieboer, 2011; Li et al., 2015). Decreased psychological well-being for caregivers of individuals with disabilities includes anxiety, depression, worry, and fear (Peer & Hillman, 2014).

As caregivers' daily lives become consumed with responsibilities associated with the child with a disability, they gradually begin to feel as if they lack control over their lives and day-to-day events (Cramm & Nieboer, 2011). Caregivers of children with disabilities focus

heavily on attending to the needs of the child with a disability, allowing for less time to be devoted to their health and self-care needs (Cramm & Nieboer, 2011; Li et al., 2015). In a 2006 study by Murphy et al. that analyzed 40 caregivers' feelings regarding their physical and emotional health as they care for their children with disabilities, caregivers reported barriers to addressing their own health needs, which included a lack of time, energy, and respite care service hours. Caregivers also neglected participation in leisure pursuits, relaxation, career exploration, and socialization with friends (Cramm & Nieboer, 2011; Lahaie et al., 2013). Caregivers often sacrifice their health and well-being to meet the extraordinary care needs of the child with a disability (Brown et al., 1993; Earle & Heymann, 2011; Li et al., 2015). The inability of caregivers to attend to personal tasks due to caregiving responsibilities creates increased caregiver stress, which decreases caregiver psychological well-being (Cramm & Nieboer, 2011).

The current COVID-19 pandemic has introduced a variety of challenges to caregivers of children with disabilities. While the nation worries about contracting the COVID-19 virus, loss of employment, and shelters in place to reduce the spread, caregivers are faced with additional worries related to raising a child with a disability (Neece et al., 2020). Neece et al. interviewed 77 caregivers of children with intellectual and developmental disabilities about the pandemic's impact on their lives as caregivers, how services have changed for their children, and their overall concerns for their children as the pandemic continues. Caregivers are expected to take on the roles of their child's educational teacher and therapist in order to continue the instructional and therapeutic programming that is now occurring virtually or completely from home (Neece et al., 2020). Caregivers expressed concern with their child lacking educational and developmental progress due to school and therapy services not

resuming and social interaction being limited (Neece et al., 2020). Approximately 48% of parents reported the greatest challenge related to the pandemic is being stuck at home and unable to leave, providing for little to no time apart from their child with a disability (Neece et al., 2020). Balancing work, caring for other children in the household that are typically developing, and lack of childcare options were reported to be the greatest challenge by approximately 17.5% of caregivers (Neece et al., 2020). In addition, caregivers reported fearing what the future may look like for their child with a disability, feeling in constant panic, and becoming bored and lonely at home (Neece et al., 2020).

Being a caregiver is a naturally stressful and complex role (Crnic & Low, 2002). A 2020 study by Marchetti et al. surveyed 1,226 parents in order to identify the prevalence of parent-related exhaustion as a result of the pandemic, as well as examine associated risk and protective factors. Marchetti et al. indicated that more than 80% of caregivers experienced high levels of parenting distress and parenting-related exhaustion, with mothers showing significantly higher psychological distress than fathers. The high levels of psychological distress discovered by Marchetti et al. may be predicted by the requirement to spend a prolonged amount of time in the caregiver role due to the COVID-19 pandemic, feelings of helplessness, lower parental resilience, social isolation, having younger children, increased care demands for children, and caring for a child with a disability.

Recurrent hospitalizations for children with disabilities may result as a consequence of poor caregiver health (Kelly & Hewson, 2000; Murphy et al., 2006). Caregivers of children with disabilities reported fearing that as their health and psychological well-being continue to decrease as a result of caregiver stress, their ability to meet the long-term needs of their child with a disability is jeopardized (Murphy et al., 2006). Due to caregiver stress and decreased

psychological well-being, caregivers feared they would be unable to provide adequate care to their child with a disability. As caregivers continue to have poor health, increased stress, and decreased psychological well-being, they may be faced with the unwanted decision to place their child out of the home (Bromley & Blacher, 1991; Kelly & Hewson, 2000; McConnell, 2015). According to McConnell et al. (2015), caregivers reported choosing out-of-home placement for their child with a disability as a result of stress and daily routines revolving around the child with a disability.

Although interventions exist to support and enhance caregivers' health and psychological well-being, caregivers claim there are not enough support services readily available, or that the services being provided are inadequate (Murphy et al., 2006). As previously mentioned, one barrier for caregivers attending to their health needs is a lack of respite care services (Murphy et al., 2006). It is also common for caregivers of children with disabilities to lack social support from friends and family members, causing them to feel isolated (Peer & Hillman, 2014; Li et al., 2015). In addition to caregiving tasks, a lack of social support and support services makes it difficult for caregivers to attend to personal health care needs or engage in desired social activities, such as socializing with friends or pursuing leisure interests (Cramm & Nieboer, 2011). Participation in informal sources of support, such as community-based respite programs or support groups, provides caregivers with social support because they know they have a network of other caregivers they can connect to and form relationships with (Murphy et al., 2006). Caregivers of children with disabilities must have stable support systems, whether it be friends, family members, professionals, or support groups, that can provide them with the support and assistance they need while caring for their child with a disability (Murphy et al., 2006).

Respite Care Services Defined

Maayan et al. (2014) define respite care services as temporary care provided to a child with a disability, with the primary goal being to provide caregivers with temporary relief. Respite care services may be planned or unplanned, can occur within the caregivers' home or within an organization, and may be provided by trained and/or untrained staff (Maayan et al., 2014). Caregivers of individuals with disabilities rely on respite care services to provide them with quality care for their child with a disability while also providing themselves with emotional, physical, and mental relief (Cowen & Reed, 2002). Respite care includes primary or secondary services (Cowen & Reed, 2002). Primary respite care services provide relief to caregivers of the individual with a disability by allowing them time away from attending to the care demands of the individual with a disability (Cowen & Reed, 2002). Secondary respite care services focus specifically on individuals with disabilities and include educational and vocational training programs, as well as support services, such as speech, physical, and occupational therapy (Cowen & Reed, 2002). Primary respite care services are most often utilized in response to family emergencies, crises, or to allow caregivers to increase engagement in routine activities, such as personal self-care, social participation, leisure exploration, and career pursuits (Cowen & Reed, 2002). Having the opportunity to experience and engage in "me time" and have scheduled personal time with minimal caregiver responsibilities significantly decreases caregiver stress (Cramm & Nieboer, 2011). As engagement in respite care services reduces caregiver stress and burden, caregivers will experience increased psychological well-being (Cramm & Nieboer, 2011).

Benefits of Utilizing Respite Care Services

Webb (2012) sampled 125 churches to analyze the role the church plays as a support

system for individuals with disabilities and compiled multiple case studies together. Primary results indicate the need for respite care services, which assist in decreasing caregiver stress and burden (Webb, 2012). It is important for church staff and volunteers to develop close relationships with families in the congregation who have children with disabilities, because it provides those families with an additional support system (Webb, 2012). One specific church in Webb's compilation of case studies, Midtown Reformed Church, developed a volunteer-based respite care program, "Special Saturdays", to support the psychological needs of caregivers of children with disabilities by providing respite services to caregivers for two hours one Saturday morning each month at the church. Siblings were invited to participate, providing caregivers a morning without any caregiving responsibilities (Webb, 2012). Besides providing relief to caregivers, the respite program, Special Saturdays, benefited the children with disabilities by offering them the opportunity to socialize and form friendships with similar peers (Webb, 2012). Growing to 20 children and approximately 30 volunteers, each child was paired with a "buddy" (a volunteer without a disability) and transitioned between multiple stations including music, crafts, a Bible story, and gross motor activities (Webb, 2012). The coordinator of Special Saturdays served as the church's special needs ministry leader, and had a full-time position in the medical field (Webb, 2012).

Rimmerman (1989) discussed the maternal stress levels of families with children with developmental disabilities after utilizing respite care services over 18 months. Seven families used respite care services and reported decreased levels of stress and appropriate coping strategies (Rimmerman, 1989). In comparison, 25 families did not utilize respite care services and reported increased stress and reduced coping strategies (Rimmerman, 1989). A study conducted by Jackson (2001) reported that 79% of caregivers experienced decreased levels of

stress and anxiety after utilizing respite care services. Botuck and Winsberg (1991) analyzed the effects of planned respite care services on school-aged children and adults with disabilities by evaluating changes in maternal mood, well-being, and activity patterns before, during, and after respite care services. Botuck and Winsberg determined that mothers claim to have improved psychological well-being, as determined by improved mood and decreased feelings of depression, while receiving respite care services, as opposed to before or after receiving respite care services.

A study conducted by Remedios et al. (2015) examined the effects of respite care services on 58 caregivers of children with disabilities. Results indicated that caregivers participated in respite care services in order to seek relief from intense caregiving responsibilities (Remedios et al., 2015). Caregivers reported experiencing decreased fatigue and that participation in respite care services was essential to their overall well-being (Remedios et al., 2015). In addition, according to a survey conducted by the Oklahoma Respite Resource Network (2004), 98% of caregivers believe respite care services make them a “better” caregiver by increasing their ability to care for their child with a disability. Caregivers of individuals with disabilities need respite care services to improve their psychological well-being, health, and quality of life by reducing stress and promoting caregiver leisure and socialization.

Marchetti et al. (2020) support the need for preventive programs to support caregivers during the COVID-19 pandemic. Marchetti et al.’s study analyzed the psychological effects of lockdown, limited social distancing, and raising a child with a disability. Healthcare professionals ought to be made aware of the overall impact had on caregivers’ and children’s psychological well-being (Marchetti et al., 2020).

Enhanced marital satisfaction, improved caregiver well-being, and increased opportunities for social participation amongst children with disabilities are themes that emerged from Whitmore and Snethen's (2018) study that analyzed caregivers' perceptions of utilizing respite care services. Caregivers often view respite care services as a "gift" because they are provided with hope and rejuvenation along what seems like an unending journey of caregiving responsibilities (Whitmore & Snethen, 2018). Caregivers reported that respite care services also benefit children with disabilities by providing them opportunities to socialize with others that are similar to them and that they relate to through shared experiences and health situations (Whitmore & Snethen, 2018). Through participation in respite care services, children with disabilities are no longer limited in their ability to form friendships and increase their social skills (Whitmore & Snethen, 2018).

Methods

Development

I focused on program development when piloting a respite care program to examine changes in caregiver burden and psychological well-being of caregivers of children with disabilities, ages 5-18. The University of Indianapolis Institutional Review Board reviewed the development of this pilot program and determined it was exempt from human research.

Needs Assessment

I conducted needs assessments with the Associate Pastor, the Director of Student Ministries/Communications and Servant Coordinator, the Director of Family Ministries, and the Communications Specialist to identify NFUMC's current conditions and desired conditions. The Communications Specialist is a caregiver of a child with a disability. The first needs assessment occurred on-site at the church and the second occurred via Zoom. Both needs assessments

followed an interview format and consisted of approximately five questions each (see Appendix A-1 and A-2 for my needs assessments). The purpose of the needs assessments was to identify needs existing in Noblesville, Hamilton County, and the church community, including strengths and weaknesses. An additional purpose of the needs assessments was to obtain information for tailoring a program to a specific target population. The development of a respite care program designed specifically for caregivers of children with disabilities was a recurring theme by all church staff. Through the administration of multiple needs assessments, I was able to obtain valuable and comprehensive information related to the church's culture, congregation, and current special needs ministries, which assisted in the development, implementation, and evaluation of the respite care program.

The demographics of NFUMC are very similar to those of the greater Noblesville community. NFUMC has a total of 882 individuals that attend all four worship services during the week. Approximately 93% of the Noblesville community speaks English, 70.0% are homeowners, 48.75% are male, 32.26% have a bachelor's degree, and 93.14% are White (U.S. Census Bureau, 2017). The average annual earning is $46,812 (U.S. Census Bureau, 2019). The overall poverty rate is 6.40% in the Noblesville community (U.S. Census Bureau, 2019). This information provided insight into the NFUMC and greater Noblesville community culture and socioeconomic status. This information was helpful when determining to whom, when, and where to advertise the respite care program.

NFUMC currently has a semi-established special needs ministry, with two main community outreach groups, Sunshine Sundays and Sunshine Friends. Both of these outreach groups within the special needs ministry primarily target adults with special needs. The church has approximately five individuals involved in Sunshine Sundays, the special needs ministry on

Sunday mornings. It was important to the pastoral staff and the special needs ministry that caregivers of children with disabilities, ages 5-18, be provided respite care services. Although there are already two existing special needs ministries within the church that provide services to individuals with disabilities over the age of 18, there were no special needs ministries providing services to the pediatric population and their caregivers. The pastor identified the church's lack of a special needs ministry and outreach program that specifically targets children and their caregivers to be both a weakness and a need for the church. The pastor also emphasized the importance of bridging the gap between community members and access to services at NFUMC, such as respite care for caregivers of children with disabilities. The pastor wanted to increase community outreach to Noblesville and the greater Hamilton County community and make families of children with disabilities more aware of services that are available to them. He was aware that one other church in the Noblesville area already promoted this service to the community, and wanted to increase the quantity and quality of services provided by the church's special needs ministry to not only its church members but also the Noblesville community and Hamilton County community.

As a result of the needs assessment, the Communications Specialist identified unmet needs she was experiencing as a caregiver of a child with a disability. She identified the importance of caregivers feeling as if the individuals providing the respite services had experience and were qualified to be caring for her child. She also expressed her appreciation for having multiple opportunities in the Noblesville area to participate in respite services, where other churches hold respite nights on different nights of the months.

Based on the results of the needs assessments, I developed, implemented, and evaluated two respite nights that occurred on the first Saturday evening of two consecutive months for

three hours. This pilot respite care program was designed specifically for children with mild to moderate disabilities, ages 5-18, with limited behavioral and medical concerns.

Capstone Plan and Process

Plan

Below you will find the goals and objectives I devised for this project after completing a thorough literature review and conducting multiple needs assessments.

1. Goal: Create a respite care program for caregivers of children with mild to moderate disabilities, ages 5-18, in order to reduce caregiver stress and burden and improve caregiver psychological well-being of 80% of registered caregivers, as evidenced by a decrease in points from pre-assessment to post-assessment on the Caregiver Burden Scale.
    a. Objective: By March 7, 2021, at least 50% of volunteers participating in the respite program will increase their overall comfort level for interacting with children with disabilities by at least one point.
    b. Objective: By April 4, 2021, at least 70% of volunteers participating in the respite program will increase their overall comfort level for interacting with children with disabilities by at least one point.
    c. Objective: By March 7, 2021, at least 50% of caregivers of children with disabilities will decrease their score from pre-assessment to post-assessment of the Caregiver Burden Scale.
2. Goal: Create various occupational therapy activities for children with disabilities that incorporate gross motor, fine-motor, and social skills, while focusing on the specific needs and interests of the children (based on formative pre-assessment).
    a. Objective: By March 7, 2021, children with disabilities will use a 5-point Likert scale

to identify the activities they preferred most during the respite nights.

3. Goal: Obtain advanced skills in the areas of management, organization, fundraising, communication, community outreach, or administration through collaboration with the directors of family ministries, special needs ministry leaders, and leaders of various church departments by assisting in three projects/events from at least four church departments (Care Team, Preschool, Sunshine Friends, Teter Farm, etc.).
    a. Objective: By January 25, 2021, I will create an online Google Excel® spreadsheet and organize it by the different ministries I am involved with at the church. I will include the advanced skill, valuable piece of information, resource, etc. I obtain from collaborating with directors of family ministries, leaders of special needs ministries, and leaders of various church departments (ex: management, organization, fundraising, communication, community outreach, administration).

Process

In order to assist me in designing, implementing, and evaluating this respite care program, I created a 14-week timeline that outlines my process for achieving these goals and objectives and carrying out the project (see Appendix B). The church provided me with a budget of $300 to purchase necessary materials for the two respite nights. I used a Microsoft Excel® spreadsheet to organize how I was spending my allotted money on the two respite nights. See Appendix C for my Microsoft Excel® spreadsheet and the budget of the two respite nights.

Project Implementation

Participants

Through advertisement of the respite care program, 11 volunteers and 7 caregivers of children with disabilities registered for the first respite night. For the second respite night, 13 caregivers and 20 volunteers registered. Volunteers could be of any age and were not required to have previous experience interacting with individuals with disabilities. I aimed for a 1:1 ratio of volunteers to children with disabilities, but still deemed it safe and appropriate to implement the program with a 1:2 ratio. According to the church's Safe Sanctuaries® policy, all events must have a 1:12 ratio of volunteers to individuals with disabilities. Approximately four church staff members were in attendance during each of the respite nights.

I contacted two large churches in Hamilton County who typically have a respite program for individuals with disabilities. I was unable to connect with one church but collaborated with the Special Needs Ministry Director of the other church and identified the consistent date and time in which their church holds their monthly respite program. I chose to schedule NFUMC's respite nights on the first Saturday of each month so it did not conflict with the other church's respite program, providing caregivers at least two opportunities to participate in respite services each month instead of just one. However, due to COVID-19, the other church decided to temporarily stop their respite program until their church gave further notice. Throughout my entire development, implementation, and evaluation process for the respite program, the other church did not hold a single respite night. Their Special Needs Ministry Director reported it had been over a year since their respite program had been functioning due to the pandemic.

I advertised the respite care program through the church's social media platforms, the lead pastor's weekly video announcements to the church congregation, weekly emails sent to the entire church congregation, and weekly announcements made during Sunday church services. I collaborated with the church's Communication Specialist and provided her with graphics and a

detailed description of the respite nights so she could email the entire church congregation and create a page for the church website. Individuals who were interested in registering for the respite nights as participants or volunteers could visit the church website to learn more information or access the registration link (See Appendix D). I also collaborated with the church's Media Specialist and provided her with graphics and a detailed description of the respite night so she could advertise the respite nights weekly on the church's social media platforms. During five Sunday mornings, I stood in front of the congregation and promoted the two respite nights.

I also advertised by passing out and posting self-created flyers in various locations throughout the Noblesville community, such as coffee shops, restaurants, toy stores, and libraries (see Appendix E for the flyer). I emailed teachers at the local school cooperation, where young adults and students may be passionate about pursuing a career related to providing services to children with disabilities. Emails were also sent to organizations involved with children with disabilities, such as the Hamilton County Special Olympics, the Boys and Girls Club, pediatric occupational and physical therapy companies, and applied behavioral analysis clinics. In order to keep track of the organizations and individuals I had contacted and planned to contact, I created a Microsoft Excel® spreadsheet and listed their contact information. Two local newspapers interviewed me and the respite program was featured in two separate newspaper columns, which provided for additional advertising (see Figures 1 and 2 of Appendix F). Promotions for the respite care program were also sent to various caregiver support groups within Facebook.

Volunteers and caregivers registered for the respite care program on the church website. I used Microsoft Word® to create two separate registration forms, one for volunteers and one for caregivers and their child(ren). I modeled my volunteer registration form after the church's pre-

existing volunteer registration form and included additional information that was specific to the respite nights. I also incorporated information from a form that the Special Needs Ministry Director from the other church in the county who was once holding respite nights provided me with when I met with him. Volunteers were required to provide information such as basic medical and personal information, their comfort levels interacting with children with disabilities in various scenarios, past experience related to interacting with children with disabilities, and whether they could attend the mandatory volunteer training session(s) (See Figures 1 and 2 of Appendix G). Volunteers were also required to complete a background check.

Caregivers were required to provide information such as basic personal and medical information for their child with a disability including disability type, behavioral and/or medical concerns, communication and ambulation techniques, sensory processing concerns, dietary restrictions, etc (see Figure 3 of Appendix G). Caregivers also provided information related to their child's interests and likes, including specific activities. I collaborated with the Communication Specialist, who converted the registration forms into an online format and uploaded them to the respite page on the church website. Individuals accessed these registration forms online and registered for the respite nights as a volunteer or registered as a participant.

I set a registration deadline for approximately two weeks prior to each respite night to ensure I had enough time to appropriately match children with volunteers. I also needed to ensure I was planning activities and stations that were of interest to the children. I allowed minimal flexibility with the deadline, especially with the volunteers, because I did not want to turn down help. During both respite nights, I had a greater number of volunteers than children, so if a caregiver registered past the registration deadline, I had flexibility in numbers. I did not turn down any caregivers who wanted to utilize the respite care service, because I recognized there to

be a great need for this service in the community. A registration deadline would ensure I was keeping the children and volunteers safe and abiding by the 1:1 or 1:2 ratio guidelines I set forth at the beginning of the project.

Project Components

Using information from the volunteer and caregiver registration forms, I strategically matched each volunteer with one or two children with a disability. Matches were made based on volunteers' comfort levels interacting with children with disabilities and the children's individual medical, behavioral, communicative, and sensory needs. Prior to each respite night, I held a mandatory training session to educate volunteers on various disability types, behavior management strategies, sensory processing information, and communication techniques when interacting with children with disabilities. The first volunteer training session occurred via Zoom due to the church not being fully reopened as a result of COVID-19. With permission from all volunteers in attendance, I recorded the first volunteer training session that was held via Zoom. I emailed the recorded training video to the church's Media Specialist who edited the video and posted it on the church website and the church's YouTube channel (see Figure 1 of Appendix H for a link to the first volunteer training session video). The purpose of posting this recorded video on the church's website and YouTube channel is for volunteers who are unable to attend future in-person training sessions to be able to refer to the training video for content knowledge related to interacting with children with disabilities. As previously mentioned, I had volunteers register the registration deadlines and volunteer training sessions had already passed. In order for these volunteers to be appropriately trained and to ensure the safety of all individuals involved during the respite nights, I referred them to the YouTube video. Individuals were required to email me and confirm they had watched the training video

prior to attending the respite night.

The second volunteer training session occurred in-person at the church with COVID-19 precautions and guidelines being followed. The second volunteer training session covered very similar content as the first volunteer training session. However, I incorporated additional content related to epilepsy and seizure first-aid, manual wheelchair use, and toileting, as there were children registered for the second respite night that had these specific needs. Similar to the first volunteer training session, the second volunteer training session was recorded and converted to a video and posted on the church's website and YouTube channel (see Figure 2 of Appendix H).

Both training sessions took place on a Tuesday evening from 7-9 p.m., approximately a week and a half prior to each respite night. I took attendance during both sessions and asked volunteers if they needed childcare to be available during the in-person training session. Zero volunteers requested childcare to be available. These volunteer training sessions also covered COVID-19 precautions and guidelines and previewed the respite nights' schedule of events. Each volunteer was provided a "cheat sheet" of basic information related to the child(ren) they were specifically matched up with and a schedule for the respite night, including a list of activities and stations. See Appendix I for an example of a "cheat sheet" that was provided to volunteers. A brief overview of the church's Safe Sanctuaries® training was provided to educate volunteers on abuse and appropriate response methods. During the in-person training session, volunteers toured the church to increase familiarity and comfort with the rooms that would be utilized during the respite night. For the training session that was held via Zoom, volunteers arrived 30 minutes early on the first respite night to receive the tour due to being unable to physically receive the tour on the night of the training session.

I created an infographic and developed an educational video for caregivers of children with disabilities discussing the importance of participating in respite care services, how respite care services can benefit them as caregivers, and the importance of incorporating respite care services into a monthly routine to establish healthy habits (see Appendix J, Figures 1 and 2). I also provided caregivers with statistics on children with disabilities and respite care services. Through the development of this video, I wanted to increase the caregivers' comfort levels of sending their child to participate in the respite program by explaining exactly what the night would entail and providing explicit details of the event. This video was created through collaboration with the church's Media Specialist. Approximately one and a half weeks prior to each respite night, I emailed the video to all caregivers who had registered for the respite night. The video was approximately ten minutes in length and was posted on the church's YouTube channel.

Based on information I received through collaboration with caregivers and after analyzing the caregivers' registration forms, I created various stations for the children to engage in during the respite nights. These stations incorporated fine-motor, gross motor, and social skills. The stations for each respite night were very similar. However, during the second respite night, I had a child with a manual wheelchair that I needed to ensure was able to participate in all of the stations and had equal access to materials and equipment. The weather was also nice outside, so I incorporated an outdoor playground station for the children to go outside in groups of two or three for approximately 15 minutes at a time. In order to ensure I had all of the necessary materials, supplies, and equipment needed for the stations, I created a list of the each station and listed individual items I would need for each station. I collaborated with the Preschool Director who provided me with a tour of the preschool facilities and all the

materials, supplies, and equipment I would be able to access during the respite nights. I created a list of the items I wanted to utilize during the respite nights and emailed this list to the Preschool Director one week prior to each respite night. I was provided access to the majority of the activities, equipment, and materials one day before each respite night and began setting up the stations. I also utilized church resources, such as crate paper, the copy machine, printer, paper shredder, paper cutter, and laminator to create an abundance of activities, signs for stations, and resources for volunteers.

As previously mentioned, the church provided me with a budget of $300 to purchase necessary materials for the two planned respite nights. The equipment and materials that I was unable to use from the church, I purchased using money from my allotted $300. Once the registration deadline for each respite night had passed, I purchased the number of necessary food items using money from my allotted $300. I also used money from the budget to purchase extra clothing items for children that needed assistance with toileting. Examples of clothing items I purchased include men's sweatpants, boy's sweatpants and shorts, and girl's sweatpants. Materials, supplies, and equipment needed for all the stations were stored in one specific location in the church.

I also collaborated with the maintenance supervisor the week prior to each respite night by providing him a visual diagram of the main room's floor layout, including the number of tables and chairs, location of tables and chairs, and location of the stations. The Preschool Director provided me with the supplies, materials, and equipment and the maintenance supervisor had all the tables and chairs set up the day before each respite night, so I began setting up the stations and activities. The week leading up to each respite night, I collaborated with the Media Specialist and completed a final walk-through of the sound booth

to practice streaming and projecting the movie, adjusting the volume, and utilizing the microphone. Approximately two days prior to each respite night, I emailed all the volunteers a list of final reminders and general responsibilities for the event (see Appendix K).

Prior to the first respite night, the volunteers arrived at 5:30 p.m. in order to sign-in, receive their name tag and Ziploc® bag filled with Clorox® disinfecting wipes, and receive their necessary paperwork for the evening, which included their "cheat sheet(s)" for the child(ren) they had been matched with and an updated schedule for the evening, including a list of the stations and activities. Volunteers also signed a document indicating they had completed the Safe Sanctuaries® training via the Zoom training session. The volunteers also received a tour of the rooms that were going to be utilized during the respite night. During the second respite night, volunteers arrived at 5:40 p.m. Although I did not need to provide volunteers with a tour on the second respite night, I wanted adequate time for volunteers to sign-in and receive their necessary items for the evening, and ensure everyone was prepared in case caregivers began to arrive early with children.

Although I set a registration deadline, and even had a few volunteers and caregivers register after the deadline, I was still prepared for caregivers to arrive on the day of the respite night and want their child to participate in the event. If this situation were to occur, my plan was for a few volunteers who were running stations and assisting with cleaning to match up with these children. Other volunteers who were assisting with cleaning and running stations would have to take over those volunteers' responsibilities.

During each respite night, caregivers dropped their child off at the church and were provided with respite care from 6-9 p.m. The first respite night was "Superhero Night" and the second respite night was "Hawaiian Night." The decorations, movie selection, activities

and station props, and freebies for the respite nights coordinated with each theme. Each child received a nametag that contained colored stickers that indicated any specific dietary, behavior, or medical needs they may have. See Appendix L for a key that indicates what each colored sticker indicated. The colored stickers were beneficial because they allowed any volunteer to quickly glance at a child and be able to identify if the child had a specific need that required extra attention and care. During the first 75 minutes of the respite night, children and their assigned volunteer rotated freely from various stations and activities. Volunteers who were not assigned to specific children with disabilities assisted with cleaning of equipment at stations, moving tables and chairs during transition periods, and ran stations to increase engagement with the children. See Figure 1 of Appendix M for a schedule of the first respite night and Figure 2 of Appendix M for a schedule of the second respite night, with each including a list of the activities and stations.

Throughout the respite night, children had access to a sensory room that consisted of sensory bins, yoga balls, a swing, bean bags chairs, rocking chairs, and a detached padded room to help self-regulate their behaviors as a result from excess external stimuli. Children also had access to sensory equipment, including headphones, chew tools, fidget spinners, and wiggle seats. COVID-19 guidelines and precautions were followed at all times during the respite nights.

In order to ensure everyone was abiding by one specific Safe Sanctuaries® guideline that requires there to be two unrelated, non-cohabitating adults in the same room with a child at all times, whenever a child needed to use the restroom, I assigned two specific volunteers to assist with this task. I encouraged all volunteers to regularly ask the child(ren) they were matched with if they needed to use the restroom. If a child needed to use the restroom, the

volunteer that was matched with that child was directed to find one of the two volunteers that had been assigned to assist with the restroom, and take the child to the restroom. The volunteer would assist the child with any necessary steps of toileting and dressing while the assigned volunteer stood halfway in the door and kept the door halfway open, making sure they could hear everything that was being said.

Whenever a child needed to utilize the sensory room, or if a volunteer believed a child would benefit from the sensory room, I assigned two specific volunteers that had previous experience related to children with sensory concerns the responsibility of ensuring they were in the sensory room with the other children and volunteers. If a volunteer wanted to utilize the sensory room, they came and told me, and then I told the volunteers that I specifically wanted to go into the sensory room with the other volunteer and child. Together, they would all go into the sensory room. I wanted to maximize my use of volunteers, so the assigned volunteers only went to the sensory room whenever a child or volunteer felt as if the child needed to utilize it. Otherwise, the volunteers acted as "floaters" and assisted with cleaning and running various stations in the large room. During the second respite night, instead of having two volunteers go into the sensory room with the volunteer and child, I had one volunteer go into the sensory room with them.

Caregivers were encouraged to provide a meal for their child in order to reduce the amount of food handling that occurred by volunteers. Pre-packaged and individually wrapped snack items were provided to all children; however, I knew many children would still be hungry. Snack items consisted of gluten-free and regular pretzels, gluten and dairy free popcorn, string cheese, and applesauce. Dietary restrictions were followed. While the children and volunteers ate, a movie played on the projector screen. After approximately 20 minutes of

eating, children had the option of continuing to sit at their table to watch the movie, or move to the floor to continue watching the movie.

During the first respite night, the children and volunteers watched a movie that was approximately 70 minutes in duration. During the second respite night, the children and volunteers watched a thirty-minute movie. With the shorter movie, children had the opportunity to rotate from various stations for an additional thirty minutes after the snack and before watching the movie. I purposefully chose to end each respite night with the children watching the movie in order to promote calming behavior prior to caregiver arrival. Approximately twenty minutes before dismissal, volunteers assisted the children in completing an exit survey, where the children rated their level of enjoyment of the various stations and activities, identified aspects they liked and disked about the evening, and indicated if they would return to future respite nights. The volunteers also completed their own exit survey and identified their comfort levels with various scenarios related to interacting with children with disabilities, provided feedback on the training session and the respite night, and indicated if they would return to future respite nights. During the second respite night, I also had the volunteers and children complete the survey 15 minutes earlier than the first respite night in order to ensure everybody had the chance to complete the form.

The week following each respite night, I sent a thank-you card to the all the volunteers, thanking them for helping during the event. Along with the formative post-assessment and summative assessment, the week following each respite night, I also sent an email to all the caregivers, providing them pictures of their child during the respite night.

Program Evaluation

I collected data from two stakeholders, the volunteers and the caregivers, in order to inform successes of the respite care program. Volunteers completed a formative pre- and post-assessment related to their comfort levels and knowledge with interacting with children with disabilities, such as changing a diaper and assisting with toileting, feeding a child, etc. Volunteers completed the pre-assessment as part of their registration form for each respite night and completed the post-assessment after participating in the mandatory volunteer training session and respite night. Volunteers who participated in both respite nights completed only one pre-assessment during the time of registration and completed two post-assessments, each occurring at the end of the two respite nights. Volunteers completed the formative post-assessments by filling out a printed document. This was earlier referred to as the "exit survey" that the volunteers completed at the end of each respite night. See Figure 1 of Appendix G for the formative pre-assessment and Appendix N for the formative post-assessment for volunteers.

I used Qualtrics to create an online questionnaire of the Caregiver Burden Scale for the caregivers' formative assessment (Zarit et al., 1980). The Caregiver Burden Scale is a self-administered questionnaire used to assess perceived burden among individuals caring for other individuals with disabilities (Zarit et al., 1980). For each caregiver that registered, I emailed them a link to the Qualtrics Caregiver Burden Scale questionnaire, along with instructions, the purpose of the questionnaire, and additional background information (see Appendix O). The Caregiver Burden Scale consists of 22 questions and takes approximately 20 to 30 minutes to complete (Rehabilitation Measures, 2021). Caregivers completed this questionnaire prior to participation in their first respite night. Within 72 hours of participating in the respite nights, I emailed each caregiver a link to the Caregiver Burden Scale (Zarit et al., 1980) and instructed caregivers to complete the questionnaire a final time. The caregivers completed a summative assessment after

participating in respite nights. Questions related to whether or not caregivers believed they would benefit from continued participation in respite care services, as well as whether or not they would participate in an additional group for caregivers of children with disabilities, offering educational sessions on how to develop healthy respite habits and routines. These questions were included within the Caregiver Burden Scale in a yes/no format. The data received from the caregivers' completion of the questionnaire after participating in the respite nights served as formative post-assessment and provided me with information on how participation in respite care services impacts their caregiver burden and psychological well-being. The data also provided valuable information on how the respite care program can continue to grow and develop in the future. See Figure 3 of Appendix N for the formative pre- and post-assessment, and Appendix P for the summative assessment for the caregivers.

In order to collect data related to the respite care program, which would be used to inform changes to the program, I created a formative post-assessment for the volunteers. Questions on this post-assessment related to the volunteers' perspective on whether they had adequate training to be successful (safe, comfortable, etc.) during the respite nights. These questions were combined with the previously mentioned formative post-assessment for volunteers to form a single document created on Microsoft Word®. Volunteers who participated in both respite nights completed two post-assessments, each occurring at the end of the two respite nights. Volunteers completed the formative post-assessments by filling out a single printed document.

I also created a formative pre- and post-assessment for the caregivers and their child with a disability. The pre-assessment was administered as part of the caregiver registration form that caregivers completed online. When registering their child, caregivers were asked to identify activities their child enjoyed. Approximately 20 minutes before leaving each respite night, the

volunteers administered the formative post-assessment to each child. This assessment consisted of questions on a document created via Microsoft Word®, surveying the child on the successes of the respite night, asking the child to rate their enjoyment level of activities using a 5-point Likert Scale, and to identify if they would return to future respite nights. This was earlier referred to as the "exit survey" that the volunteers assisted the child with completing at the end of each respite night. See Figure 2 of Appendix N for the formative post-assessment for the children.

Program Results

Microsoft Excel® spreadsheets were created and utilized to track pre- and post-assessment data for volunteers, caregivers, and children with disabilities for each of the two respite nights.

Respite Nights' Caregivers, Volunteers, and Children

Caregivers

Although seven children participated in the first respite night, one caregiver did not complete the pre-assessment and one caregiver had two children that participated, with one child having a disability and the other child being a sibling that was neurotypical. Caregiver burden was measured using Zarit et al.'s (1980) Caregiver Burden Scale. The minimum clinically important difference for the Caregiver Burden Scale by Zarit et al. (1980) is five points (Fekete, 2017). When analyzing the formative pre- and post-assessment data using the Caregiver Burden Scale (Zarit et al., 1980), and the summative assessment data of the caregivers, I quickly noticed that prior to the first respite night, 80% of caregivers experienced "Moderate to Severe" caregiver burden. After the first respite night, only one caregiver experienced a decrease in caregiver burden, where their pre-assessment score on Zarit et al.'s (1980) Caregiver Burden Scale decreased by 10 points, which is significant. Prior to participating in the first respite night,

this caregiver fell into the "Moderate to Severe" burden category. However, after participating in the first respite night, they dropped down one burden category to "Mild to Moderate." As a group, the five caregivers' average caregiver burden increased when comparing their scores prior to and after participating in the first respite night. However, the increase in scores was not significant because it was less than five points (Fekete, 2017). As a group, the five caregivers had an average pre-assessment mean score of 41.80 prior to the first respite night, placing them in the burden category of "Moderate to Severe." After participating in the first respite night, the caregivers had an average post-assessment mean score of 46.00, placing them in the burden category of "Moderate to Severe." The caregivers' positive verbal feedback when picking up their children at the end of the first respite night, along with their feedback on the summative assessments, did not align with the data on the formative post-assessments. All caregivers reported they benefited from the first respite night and would participate in future respite nights. This information is discussed in detail in the "Discussion" section of the paper.

See Table 1 below for detailed information of each caregivers' burden levels prior to and after participating in the first respite night.

Table 1

First Respite Night Caregiver Burden

First Respite Night Caregiver Burden				
Caregiver	Pre-Assessment Mean Score	Post-Assessment Mean Score	Pre-Burden Category	Post-Burden Category
1	43.00	59.00*	Moderate to Severe	Moderate to Severe
2	45.00	35.00*	Moderate to Severe	Mild to Moderate
3	42.00	51.00*	Moderate to Severe	Moderate to Severe
4	36.00	37.00	Mild to Moderate	Mild to Moderate
5	43.00	48.00*	Moderate to Severe	Moderate to Severe

Note. Comparison of the amount of caregiver burden experienced by each caregiver prior to and after participating in the first respite night, as measured by Zarit et al.'s (1980) Caregiver Burden Scale.

* = clinically significant, MCID = 5 points (Fekete, 2017). Highlighted data indicates a change in burden category.

Table 2

First Respite Night Caregiver Burden Group Average

First Respite Night Caregiver Burden Group Average			
Average Pre-Assessment Mean Score	Average Post-Assessment Mean Score	Average Pre Burden Category	Average Post Burden Category
41.80	46.00	Moderate to Severe	Moderate to Severe

Note. Comparison of the average amount of caregiver burden experienced by caregivers prior to and after participating in the first respite night, as measured by Zarit et al.'s (1980) Caregiver Burden Scale.

I initially had sixteen children and thirteen caregivers register to participate in the second respite night. However, two caregivers had to cancel due to COVID-19 and five caregivers had to cancel due to changes in Easter plans and/or Spring break. Six caregivers and eight children participated in the second respite night, with all caregivers completing the formative pre-assessment and five caregivers completing the formative post- and summative assessments. The caregiver that initially registered their child with a disability who was planning to be in a manual wheelchair the entire duration of the second respite night did not participate in the event. Two caregivers had two children each participate, with one child having a disability and the other child being a sibling that was neurotypical. Using the Caregiver Burden Scale on both the formative pre- and post-assessments, as well as the summative assessment, I discovered that prior to the second respite night, 17% of caregivers experienced "Severe" caregiver burden, 50% of caregivers experienced "Moderate to Severe" caregiver burden, and 33% of caregivers experienced "Mild to Moderate" caregiver burden (Zarit et al., 1980). Two caregivers that participated in the second respite night also participated in the first respite night. After participating in both respite nights, one caregiver experienced an increase in caregiver burden from 35.00 to 38.00 using Zarit et al.'s Caregiver Burden Scale, which is not significant because

it is less than 5 points (Fekete, 2017). The other caregiver did not experience a change in caregiver burden and remained at 48.00 on Zarit et al.'s Caregiver Burden Scale.

After the second respite night, three caregivers experienced a decrease in caregiver burden, where their pre-assessment score on Zarit et al.'s (1980) Caregiver Burden Scale decreased. Two caregivers experienced a significant decrease in caregiver burden, where their scores on Zarit's Caregiver Burden Scale decreased by at least 5 points (Fekete, 2017). These two caregivers also experienced changes in their burden category (Zarit et al., 1980). Prior to participating in the second respite night, one caregiver fell into the "Moderate to Severe" burden category and the other caregiver fell into the "Severe" burden category. However, after participating in the second respite night, one caregiver dropped down one burden category to "Mild to Moderate" and the other dropped to "Moderate to Severe." As a group, the five caregivers had an average pre-assessment mean score of 47.00 prior to the second respite night, placing them in the burden category of "Moderate to Severe." After participating in the second respite night, the caregivers had an average post-assessment mean score of 45.20, placing them in the burden category of "Moderate to Severe." The caregivers' positive verbal feedback when picking up their children at the end of the second respite night, along with their feedback on the summative assessments, partially align with the data on the formative post-assessments. All caregivers reported they benefited from the second respite night and would participate in future respite nights. This information is discussed in detail in the "Discussion" section of the paper.

Table 3

Second Respite Night Caregiver Burden

Second Respite Night Caregiver Burden				
Caregiver	Pre-Assessment Mean Score	Post-Assessment Mean Score	Pre-Burden Category	Post-Burden Category
1	45.00	38.00*	Moderate to Severe	Mild to Moderate
2	43.00	48.00*	Moderate to Severe	Moderate to Severe
3	42.00	48.00*	Moderate to Severe	Moderate to Severe
4	39.00	36.00	Mild to Moderate	Mild to Moderate
5	66.00	56.00*	Severe	Moderate to Severe

Note. Comparison of the amount of caregiver burden experienced by each caregiver prior to and after participating in the second respite night, as measured by Zarit et al.'s (1980) Caregiver Burden Scale.
* = clinically significant, MCID = 5 points (Fekete, 2017). Highlighted data indicates a change in burden category.

Table 4

Second Respite Night Caregiver Burden Group Average

Second Respite Night Caregiver Burden Group Average			
Average Pre-Assessment Mean Score	Average Post-Assessment Mean Score	Average Pre Burden Category	Average Post Burden Category
47.00	45.20	Moderate to Severe	Moderate to Severe

Note. Comparison of the average amount of caregiver burden experienced by caregivers prior to and after participating in the second respite night, as measured by Zarit et al.'s (1980) Caregiver Burden Scale.

Volunteers

A total of 11 volunteers participated during the first respite night. Out of the 11 volunteers, 7 of them attended the Zoom training session. The other 4 volunteers were either unable to attend the session or registered past the registration and training session deadline and were required to watch the recorded video of the training session on the church's YouTube channel.

I analyzed the 11 volunteers' formative pre- and post-assessment data from the first respite night to compare their comfort levels in each category using a 5-point Likert Scale for comfort (see Table 5 below).

Table 5

Volunteers' Change Score Post First Respite Night and Training Session

Volunteers' Change Score Post First Respite Night and Training Session						
Change in Score (Using 5-point Likert Scale for Comfort)	Changing Diaper/ Assisting with Toileting	Slobber/ Drooling	Redirecting Child Who is Refusing	Assisting Child with Feeding	Addressing Challenging Behaviors	Overall Comfort Level
0	10	8	9	7	6	8
1	1	2	1	4	3	3
2	0	1	1	0	2	0

Note. The number of volunteers who experienced each change in score using a 5-point Likert Scale for comfort when comparing the 11 volunteers' formative pre- and post-assessment data from the first respite night for each category.

Using a 5-point Likert Scale, the 11 volunteers had an average overall comfort level of 4.0 prior to attending the training session and participating in the first respite night. After attending the training session and participating in the first respite night, volunteers had an average overall comfort level of 4.3, using a 5-point Likert Scale. None of the volunteers indicated they required additional training or education in order to be successful or feel more comfortable in future respite nights. All of the volunteers indicated they would be interested in volunteering again for future respite nights. Six of the volunteers signed up to participate in the second respite night. The other volunteers reported that the primary conflict was that the second respite night was the same weekend as Easter and they had prior commitments with family.

When analyzing the volunteers' formative post-assessment data, which was completed at the end of the first respite night, a few themes that emerged were reducing the film length, increasing the length of time to engage in activities and stations, and having more physical activity stations. This feedback was consistent with the feedback on the children's formative post-assessments. One volunteer recommended I also place balloons or a sign outside the door I wanted caregivers to drop off their child at, in order to more clearly indicate to caregivers where they were supposed to enter. I implemented these changes during the second respite night.

A total of 20 volunteers initially registered for the second respite night. One volunteer cancelled their registration due to changes in Easter plans one day prior to the second respite night. On the day of the second respite night, five additional volunteers did not participate due to their child no longer being able to participate in the second respite night due to changes in Easter plans and/or sickness. A total of 14 volunteers participated in the second respite night. Out of the 14 volunteers, 12 of them attended the in-person training session. The other two volunteers were unable to attend the session and were required to watch the recorded video of the training session on the church's YouTube channel.

I analyzed the 14 volunteers' formative pre- and post-assessment data from the second respite night to compare their comfort levels in each category using a 5-point Likert Scale for comfort (see Table 6 below).

Table 6

Volunteers' Change Score Post Second Respite Night and Training Session

Volunteers' Change Score Post Second Respite Night and Training Session						
Change in Score (Using 5-point Likert Scale for Comfort)	Changing Diaper/ Assisting with Toileting	Slobber/ Drooling	Redirecting Child Who is Refusing	Assisting Child with Feeding	Addressing Challenging Behaviors	Overall Comfort Level
-2	1	1	0	0	0	0
-1	1	2	1	3	1	1
0	8	7	8	7	7	8
1	2	2	2	3	2	4
2	0	2	3	1	3	0
3	1	0	0	0	1	1
4	1	0	0	0	0	0

Note. The number of volunteers who experienced each change in score using a 5-point Likert Scale for comfort when comparing the 14 volunteers' formative pre- and post-assessment data from the second respite night for each category.

Using a 5-point Likert Scale, the 14 volunteers had an average overall comfort level of 3.9 prior to attending the training session and participating in the second respite night. After attending the training session and participating in the second respite night, volunteers had an average overall comfort level of 4.4, using a 5-point Likert Scale. One volunteer indicated they required additional training or education, specifically as it related to assisting a child with transitioning to different activities, in order to be successful or feel more comfortable in future respite nights. All of the volunteers indicated they would be interested in volunteering again for future respite nights. When analyzing the volunteers' formative post-assessment data, which was

completed at the end of the second respite night, there was not any feedback regarding program development. Common themes that emerged from the data were that the respite night was very organized, and the training session was thorough and made the volunteers feel well prepared.

I combined all volunteers from the first and second respite night, which provided for a total of 21 volunteers. Using a 5-point Likert Scale, the 21 volunteers had an average overall comfort level of 3.9 prior to attending the training session and participating in either respite night. After completing the training session and participating in either respite night, volunteers had an average overall comfort level of 4.3, using a 5-point Likert Scale.

Children

When analyzing the children's formative post-assessment data, or "exit surveys" that the volunteers assisted the children in completing at the end of the first respite night, a few themes emerged. These themes included shortening the movie time, incorporating outside activities, and incorporating more games and physical activity. One child with sensory concerns indicated he enjoyed the sensory room and crafts. Themes from the children's feedback and from my informal observations indicated the need to decrease the duration of the movie, as children were becoming distracted and losing attention with the 70-minute movie. During the first respite night, the children found the most enjoyment in eating the meal and snack, playing with the various playground balls, tossing the bean bags, shooting basketball, playing musical instruments, making the craft, and socializing with others. On the children's formative post-assessment, all of the listed activities were rated a "5" on a 5-point Likert Scale, indicating the children "really enjoyed" the activities. Five out of seven children rated the respite night to be a "5" on a 5-point Likert Scale, indicating they "really enjoyed" the evening. The other two children did not answer that specific question. All seven children

indicated they had fun and would return to future respite nights.

During the first respite night, I realized there were a few children that I should not have paired up together due to sensory and behavioral concerns, as well as personality differences. I could solely go off of as much or as little information as the caregivers provided on the formative pre-assessment data form, or the registration forms when they registered their child. However, after having the opportunity to see the children engage in activities during the first respite night, I was able to use observation skills and obtain greater insight into each child's true sensory and behavioral needs. During the first respite night, I paired four volunteers with seven children. This allowed for three volunteers to be matched with two children and one volunteer to be matched with one child. The remaining five volunteers acted as "floaters" and ran stations, assisted with moving tables and chairs, and provided an extra set of hands with cleaning equipment. However, during the second respite night, all of the volunteers were matched up with one child. I used my observations from the first respite night to more appropriately match children with volunteers. All children that participated in the first respite night registered for the second respite night. However, due to changes in Easter plans, only three of the eight children that attended the second respite night also attended the first respite night.

When analyzing the children's formative post-assessment data from the second respite night, there were no common themes related to program development. The children found the most enjoyment in playing outside on the playground, eating the meal and snack, shooting basketball, playing musical instruments, shaking the parachute, using the building blocks, and socializing with others. All of the listed activities were rated a "5" on a 5-point Likert Scale, indicating the children "really enjoyed" the activities. Six out of the seven children that

completed the formative post-assessment rated the second respite night to be a "5" on a 5-point Likert Scale, indicating they "really enjoyed" the evening. This provided for a group average enjoyment rate of 4.6. The other child did not complete a formative post-assessment due to his severe cognitive disability. All seven children indicated they had fun and would return to future respite nights.

I made adjustments for the second respite night to incorporate more gross motor and high-energy stations and activities, focusing specifically on ensuring these stations were inclusive, and accessible to the child I had register for the second respite night that was going to be in a manual wheelchair. Due to that child not participating in the second respite night, I was unable to assess and observe whether or not the stations and activities I created would provide the child equal access to all materials and equipment.

Discussion and Implications for Practice

As the number of children being diagnosed with developmental and intellectual disabilities continues to increase, so do the number of caregivers taking on the responsibilities of providing care for these children and ensuring their needs are being met (Zablotsky et al., 2019). In order to ensure the caregivers' needs are being met, participation in respite care services is extremely beneficial. There were multiple key findings I discovered while completing my DCE project of developing, implementing, and evaluating a respite care program. When reflecting on the results and objectives I set forth at the beginning of the project, and synthesizing information from the literature review, the key findings of this pilot respite program suggest caregivers' participation in a respite care program are beneficial to reduce caregiver burden and improve psychological well-being.

My primary goal was to create a respite care program for caregivers of children with disabilities, ages 5-18, in order to reduce caregiver stress and burden and improve caregiver psychological well-being. I specifically had a goal for at least 80% of caregivers to decrease their score on the formative pre- to post-assessment, which consisted of Zarit et al.'s (1980) Caregiver Burden Scale. A decrease in score would indicate a decrease in caregiver burden and improvement in psychological well-being. After the first respite night, only one of five caregivers, or 20% of caregivers, experienced a decrease in caregiver burden, as measured by a change in score of at least 5 points on Zarit et al.'s Caregiver Burden Scale. After the second respite night, three of five caregivers, or 60% of caregivers, experienced a decrease in caregiver burden, as measured by a change in score of at least 5 points on Zarit et al.'s Caregiver Burden Scale. However, the caregivers' written feedback on the summative assessment they completed after participating in both the first and second respite nights did not support this quantitative data. Multiple caregivers made comments about how participating in the respite nights was the first time they had been out together as a couple in over a year, how they felt relieved to be able to take their child out of the house instead of only having people over to their house, and how the event lifted their moods and spirits. One caregiver reported it would be beneficial for multiple churches to develop respite nights and have the nights occur on different days of the month, providing caregivers the opportunity to have multiple times a month to tend to their own needs. From both respite nights, all caregivers indicated they would benefit from continued respite care services and eight out of nine caregivers, or 89% of caregivers, indicated they would benefit from an additional group that offered educational sessions on how to develop healthy respite habits and routines. Due to time constraints with the DCE only being 14 weeks, I was unable to develop and implement an educational group for caregivers that related to developing healthy

respite habits and routines. My inability to develop this additional group may be the reason why I was unable to successfully reach this goal.

Two caregivers participated in both respite nights. After participating in both respite nights, one caregiver experienced an increase in caregiver burden by three points using Zarit et al.'s (1980) Caregiver Burden Scale, although this was not significant because it was not greater than five points (Fekete, 2017). The other caregiver did not experience a change in the amount of caregiver burden they were experiencing. Caregivers may not have experienced a significant decrease in caregiver burden due to them only participating in one or two respite nights and not incorporating self-care strategies as part of a routine.

In a 2013 study, Carter and Mandrell created a pilot hospital-based respite care program for children with cancer in order to reduce caregiver stress. Volunteers were hospital staff and were required to complete a pre-questionnaire, a satisfaction survey to assess their comfort levels and determine their fit for the role, a background check, and attend a mandatory 3-hour training session (Carter & Mandrell, 2013). After completion of the pilot program, caregivers and staff were surveyed using a 4-point Likert Scale, with results indicating a strong desire for continuation of the respite program (Carter a& Mandrell, 2013). The formal respite program provided respite services to the children seven days a week. Carter and Mandrell concluded that although their program is specific to children with cancer, their program model is successful and applicable to most pediatric care sites.

Neufeld et al. (2001) surveyed caregivers of children with chronic conditions on the type of respite services they utilize. Results concluded that 73% of caregivers rely on formal respite services at least once a month and 55% of caregivers rely on in-home babysitting for their child at least once a month (Neufeld et al., 2001). The authors reported that 40% of

caregivers utilize respite camps for their older children with disabilities (Neufeld et al., 2001).

Carter and Mandrell's (2013) respite care program provides caregivers with consistency and routine. Neufeld et al.'s (2001) study indicated that caregivers typically require and utilize respite services on a monthly basis. Caregivers will likely experience a more significant decrease in caregiver burden and improved psychological well-being if they consistently participate in a monthly respite program. Being provided the opportunity to engage in self-care tasks, leisure pursuits, and socialization for three hours one time a month for one or two months does not constitute enough time for caregivers to experience a true change in caregiver burden. As time progresses, and caregivers continue to consistently participate in NFUMC's respite program by incorporating it into their routine in order to establish a healthy habit, they will likely experience decreased caregiver burden and improved psychological well-being due to increased frequency and participation in self-care.

When developing, implementing, and evaluating the pilot respite care program at NFUMC, I utilized a similar program model as Carter and Mandrell (2013). The authors discussed the high importance of the post-surveys using the 4-point Likert Scale, which provided critical feedback for program development. Within my project, I found these post-assessments to be extremely informative because they allowed me to make vital changes between the first and second respite nights. These changes increased the children's engagement in fine-motor, gross motor, and social skill activities and reduced the chance of challenging behavior to occur.

I had an objective for at least 80% of volunteers participating in the respite program to increase their overall comfort level for interacting with children with disabilities by at least one point after completing the required volunteer training session and participating in the

respite nights. Four volunteers participated in both respite nights. During the first respite night, 27% of volunteers had an increase in their overall comfort level. During the second respite night, 36% of volunteers had an increase in their overall comfort level. One possible reason for volunteers not having change in scores in individual categories and overall comfort levels is because they are current or retired licensed special education teachers, healthcare professionals who have experience interacting with children with disabilities (i.e. occupational therapist, registered nurse, applied behavioral analysis therapist), are active or have been active volunteers in the church's other special needs ministries, and/or are raising children with disabilities.

When promoting the pilot respite program, I informed caregivers that all volunteers would be trained and educated prior to each respite night. The required training sessions were advertised on the flyers and the church website for both caregivers and volunteers to see. Requiring all volunteers to complete the 2-hour training session prior to participating in each respite night ensured all volunteers were well equipped to interact with the children with disabilities during the respite nights and helped ensure the safety of all individuals in attendance (Carter & Mandrell, 2013). As supported by the feedback received after caregivers participated in the respite nights, caregivers experienced increased comfort and trust knowing their children were dropped off at respite night with volunteers who had completed a 2-hour training session. These mandatory training sessions are a key component of the respite program moving forward. It is critical to have trained and educated volunteers, as it increases caregivers' comfort levels and confidence levels when participating in respite services. Having trained and educated volunteers also increases the various diagnoses and health care needs the volunteers are capable of appropriately and safely accommodating and tending to

when interacting with the children with disabilities during respite nights (Whitmore & Snethen, 2018).

I devised a goal for the children with disabilities to engage in a variety of stations that incorporated aspects of occupational therapy, such as gross motor, fine-motor, and social skills. Choosing the stations based on information identified on the children's formative pre-assessment that was completed at registration was important, as it enabled me to ensure I was appropriately matching activities to the children's cognitive, behavioral, sensory, and communicative needs and concerns. By implementing the formative post-assessment after the children participated in the respite night, I was able to track which activities the children preferred most. I was then able to make adjustments related to program development and meet the children's needs and desires more appropriately during the second respite night. For future respite nights to be successful, this process should continue.

Limitations

Although there were many strengths of the respite program, it is important to recognize that limitations did exist. Limitations of the respite care program were that I was only provided the opportunity to pilot the respite program through the development, implementation, and evaluation of two respite nights. My role through this process was to develop a fully functional respite care program that NFUMC could continue implementing at the end of my DCE in order to decrease caregiver burden and improve psychological well-being, as well as continue engaging in community outreach. In order for the caregivers to truly experience a decrease in caregiver burden and improved psychological well-being, I would need to continue implementing the program and have the caregivers incorporate respite services into their routine.

As discussed in the literature review, another limitation was that caregivers were likely experiencing increased caregiver burden due to additional caregiving responsibilities and stresses as a result of the COVID-19 pandemic. This may have negatively impacted the amount of relief and decreased caregiver burden caregivers experienced through participation in the respite nights. If caregivers were experiencing a heightened level of caregiver burden, they may require more consistent respite services to experience a significant decrease in caregiver burden and improved psychological well-being.

The date of the second respite night was a limitation, as it was planned for the Saturday of Easter. Multiple caregivers registered and then cancelled the day of the second respite night due to changes in Easter plans. Those caregivers were unable to attend and did not receive the respite services they had been planning on for a month, which may inadvertently had the opposite impact on their caregiver burden and psychological well-being. Although the respite nights were scheduled based on NFUMC's availability and when the church deemed the event would be most successful, more appropriate scheduling of future respite nights should occur to enable caregivers to participate in the maximum number of respite nights. In addition, sustainability of the respite care program moving forward may be a limitation. See "Site and Community Impact" below for issues related to the sustainability of the respite care program.

Impact of DCE

Personal Impact

While completing my DCE at NFUMC, I discovered myself growing both personally and professionally. Personally, I increased my self-confidence through leading the volunteer training sessions. I am no longer fearful to stand in front of a large crowd and talk about

topics I am passionate and knowledgeable about. I also improved my communication skills when conversing with caregivers and community organizations. My passion and heart for serving those with disabilities, and whom those with disabilities directly impact, grew even greater through this project.

Professionally, I obtained in-depth knowledge on the role occupational therapy can play on psychological well-being, especially as it relates to caregivers providing care for children with disabilities. There are numerous aspects, as well as large and minute details that go into developing an entire program. I believe I have acquired the organizational skills necessary to develop a concrete, sustainable program that can be implemented for years to come and be of benefit for stakeholders. Through the development, implementation, and evaluation of the respite care program, I obtained skills related to the administration and interpretation of informal assessments, data collection, and data analysis. Specifically, I analyzed information related to children's cognitive, medical, behavioral, communicative, and sensory needs to ensure I matched them with the appropriate volunteers. As a future occupational therapist, I will utilize a holistic approach and these same clinical skills on a daily basis when providing services to clients. In addition, I established connections with multiple community organizations that could potentially benefit me in the future, whether I am searching for a job position as an occupational therapist or helping the church recruit potential volunteers for future respite nights.

Besides developing, implementing, and evaluating the respite care program, I also created a goal to obtain advanced skills in the areas of management, organization, fundraising, communication, community outreach, and/or administration through collaboration with the directors of family ministries, special needs ministry leaders, and leaders of various church

departments by assisting in three projects/events from at least four church departments. Not only did I obtain these skills through the development of the respite program, but I also obtained these skills through my collaboration with other church ministries and leaders. During my first two weeks at NFUMC, I created an online Google Excel® spreadsheet and organized it by the different ministries I was involved with at the church. I included the advanced skill, valuable piece of information, resource, etc. I obtained from collaborating with different individuals within the church (see Appendix Q for my Excel® spreadsheet of the advanced skills I obtained through collaboration with various church ministries).

Site and Community Impact

By developing and implementing this respite care program at NFUMC, I had the opportunity to educate church staff members about children with disabilities and the amount of caregiver burden that caregivers experience due to caregiving responsibilities associated with caring for a child with a disability. The church benefitted by learning to be more inclusive of children with disabilities and their families. NFUMC will continue to benefit because the development of this respite program is a method of community outreach to the greater Noblesville community. Families with children with disabilities in the Hamilton County area are now more aware of services that are available to them, and how these services can benefit them long-term. The lead pastor wanted to increase the quantity and quality of services provided by the church's special needs ministry to not only its church members but also the Noblesville and Hamilton County community.

This program benefits the caregivers because although many of them did not experience a significant decrease in caregiver burden, as measured by Zarit et al.'s (1980) Caregiver Burden Scale, their feedback indicated that participating in this respite care

program was beneficial. They are provided the opportunity to spend three hours, uninterrupted, without any caregiving responsibilities, engaging in self-care, socializing with friends, participating in leisure activities, etc. The children with disabilities benefit because they participate in activities that incorporate fine-motor, gross motor, and social skills into them. The children are also provided the opportunity to form friendships and engage in socialization with similar peers during the respite nights. These social skills are critical for child development and during transitional periods, such as from high school to adulthood.

NFUMC and Hamilton County will continue to benefit from this respite program, as the church has decided to continue implementing quarterly respite nights beginning in August. They plan to take the summer months off to provide families the opportunity to spend quality time together due to children being out of school, travel if they wish, and enjoy the weather outside. The Director of Family Services plans to take over the responsibilities associated with planning and implementing the respite nights, as she has prior experience with organizing respite nights from her previous leadership positions at different churches. I have shared all of the resources, documents, and materials with NFUMC via Google Drive and plan to remain in contact with the Director of Family Ministries to assist with planning and implementation of future respite nights. I also plan to prepare and lead all required volunteer training sessions prior to each respite night. NFUMC already has the next two respite night dates scheduled and confirmed on the calendar. The Autism Society of Indiana reached out to the church asking to form a partnership for future respite nights. The Autism Society of Indiana is going to advertise the respite care program on their website, social media platforms, and pass out promotional flyers.

Professional Impact

Through the development, implementation, and evaluation of this respite care program, I was provided the opportunity to advocate for the profession of occupational therapy. I often engaged in conversations with church staff members and church members about how the respite program was going. Many of these individuals would ask me to define occupational therapy and/or the purpose of the respite program. Whenever I engaged in conversations about the respite program, I strived to incorporate aspects of occupational therapy into the conversations in order to raise awareness about the profession. The flyers I created to promote the respite nights, as well as the registration page on the church website, included information related to occupational therapy. In addition, one specific caregiver was interested in learning more about how occupational therapy services could benefit her daughter with a disability. I engaged in conversation with her about the role occupational therapy plays in pediatrics and school-based settings, and discussed how occupational therapy could benefit her daughter. I also emailed her resources.

Conclusion

The development of this respite care program increases the quality and quantity of services readily available to caregivers of children with special needs in Noblesville and Hamilton County. Access to respite care services is now less of a barrier for caregivers tending to their health needs. Consistent participation in respite care services and incorporating respite care services into a healthy habit and routine will reduce caregiver burden and improve psychological well-being.

NFUMC has a fully functional respite care program that benefits both caregivers and children with special needs. I have obtained many skills and an abundance of knowledge through the development, implementation, and evaluation of this respite care program. I am

looking forward to seeing how this DCE project continues to impact NFUMC, Noblesville, Hamilton County, and the profession of occupational therapy.

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Appendix A-1

Needs Assessment #1
1.30.2020
On-site with Associate Pastor

1. What are the current strengths of the church?
    a. Special needs ministry, Sunshine Friends, has been operating for over thirty years and has great community outreach
    b. Multiple outreach ministries within the church
2. What are the current weaknesses of the church?
    a. Lack of connection between outside community members with disabilities and the church
    b. Volunteers are so committed to their current ministries that the church does not want to overwhelm them, would likely need to recruit new volunteers if developed a new program
    c. Special needs ministry on Sunday mornings, Sunshine Sundays, primarily consists of adults with special needs – no ministry focuses on children with disabilities or caregivers of children with disabilities
    d. Larger churches in the area have previously had respite nights for caregivers of children with disabilities
3. What are the current needs of the church?
    a. Expand Sunshine Sundays to include children with disabilities
    b. Provide support for caregivers of children with disabilities
    c. Parent support group for individuals with disabilities
        i. Educational sessions during the week
    d. Increase community outreach to greater Noblesville community
4. What are the church's demographics?
    a. ~1,000 members attend all 4 services throughout the week
5. Can you describe the church's current special needs ministries and outreach programs?
    a. Sunshine Friends
    b. Sunshine Sundays

Appendix A-2

Needs Assessment #2

5.22.2020

Via Zoom with Director of Student Ministries/Communications and Servant Coordinator, the Director of Family Ministries, and Communications Specialist (caregiver of a child with a disability)

1. How do you recruit volunteers for other outreach ministries?
    a. Advertise via social media, flyers
    b. Sign-up online via church website
2. Is it most important for me to target the caregivers of the children with disabilities or the children with disabilities?
    a. Impact of COVID-19 on caregivers' psychological well-being
    b. Primary focus is on the caregivers
3. What impact will COVID-19 have on the respite care program?
    a. "Buddy system"
    b. Safety precautions
    c. 1:1 ratio
4. What unmet needs do you have as a caregiver of a child with a disability? (directed toward Communications Specialist)
    a. Lack of quality time with spouse
    b. Constantly "on the go"
    c. Education on various disability topics – could benefit from parent support group
        i. Church has tried it in the past
    d. Knowing my child is safe and in "good hands" when we are participating in respite
    e. Contact local churches to ensure respite program does not conflict with other respite opportunities
        i. Would be great to create additional respite opportunities for caregivers

Appendix B
14-Week Timeline

Week 1 (Jan 11-Jan 17)

- Orientation to DCE site
- Organize DCE paper
- Revise literature review
    - Research COVID's impact on mental health and raising children with disabilities
- Create an online Google Doc Excel spreadsheet for each advanced skill, valuable piece of information, resource, etc. I obtain from collaborating with directors of family ministries, leaders of special needs ministries, leaders of special needs ministries, and leaders of various church departments
- Write up informal presentation to present during worship service
    - Explain purpose of respite nights
    - Provide supporting research
    - Explain how caregivers of individuals with disabilities will benefit by participating in program – begin to incorporate it into a routine and healthy habit, reduce stress, anxiety, and caregiver burden which will improve psychological well-being
    - Explain how church members can become involved
- Create timeline for DCE
- Register with Square
- Register with Mail Chimp
- Staff meeting – 1/12 Zoom @ 9
- Wednesday meeting with Ally @ 10
- Weekly forum – due 1/11

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 2 (Jan 18-Jan 24)

- Create group on MailChimp for community resources/organizations I want to advertise to
- Create flyers to advertise at local businesses, church, community, etc.
- Make a contact list using Excel spreadsheet for schools, businesses, organizations, etc. I want to reach out to in order to obtain participants and volunteers – advertise respite program
- Contact and collaborate with church's Communication Specialist, Kathy Tomes
    - Provide her with text and graphics to email to entire church congregation to advertise respite nights
- Email church's Communications Specialist a one-page report explaining respite nights so she can create a page for the church website
    - Purpose
    - How to register
    - Respite night dates, registration deadlines, training session dates
- Begin to contact community organizations via email and phone to advertise for the respite program and recruit participants and volunteers (Boys and Girls Club, Special Olympics, nursing homes, YMCA, ABA clinics)
- Write up informal presentation to present during worship service
    - Explain purpose of respite nights
    - Provide supporting research
    - Explain how caregivers of individuals with disabilities will benefit by participating in program – begin to incorporate it into a routine and healthy habit, reduce stress, anxiety, and caregiver burden which will improve psychological well-being
    - Explain how church members can become involved
- Update Needs Assessment
- Update Goals and Objectives
- Staff meeting – 1/19 Zoom @ 9
- Family Ministry Meeting – 1/19 Zoom @ 11:30
- White River Christian Church Meeting – 1/19 @ 2
    - Meeting was with special needs pastor and respite night director, Paul Hathcoat
    - Discussed logistics of respite night
- Wednesday meeting with Ally @ 10
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 3 (Jan 25-Jan 31)

- Email Ally text and graphics to include in her February weekly emails
- Create registration forms for volunteers and caregivers using Word
    - Email to Communications Specialist so she can convert them to online format and post on the church website via a registration link
- Research appropriate outcome measures - Caregiver Burden Scale
- Utilize Qualtrics to create formative and summative assessments for caregivers of children with special needs based on Caregiver Burden Scale outcome measure
- Create flyers to advertise at local businesses, church, community, etc.
- Begin to contact community organizations via email and phone to advertise for the respite program and recruit participants and volunteers (Boys and Girls Club, Special Olympics, nursing homes, YMCA, ABA clinics)
- Decide on theme for first and second respite night
    - First = Superhero
    - Second = Hawaiian
- Begin to create social skills activities/games for the Social Skills station during the first respite night
    - Used Teacher Pay Teacher
- Begin to create and develop activities, supplies, and equipment needed for stations during 3/6 respite night
    - Create a Word document for each respite night and include the stations I wanted to have at each respite night
    - List the materials, supplies, and equipment that needs to be created and/or purchased for each station
- Contact and collaborate with church's Media Specialist, Alivia Dieterlen, to coordinate filming an educational video for the caregivers
- As participants (caregivers) register for respite night, email them the link to the Qualtrics formative pre assessment based on the Caregiver Burden Scale outcome measure
- Create Excel spreadsheet to convert and organize the data from Qualtrics formative pre and post assessments and summative post assessment for Caregiver Burden Scale
- Create Excel spreadsheet to organize the data from the formative volunteer pre and post assessment
- Revise theory/framework
- Research journal options for publication
- Write Background/Introduction for DCE paper – Due next Monday 2/1
- Staff meeting – 1/26 Zoom @ 9
- Safe Sanctuaries Training – Tom @ 2:30 Zoom
- Wednesday meeting with Ally @ 10
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 4 (Feb 1-Feb 7)

- Organize outcome measures
- Write Methods for DCE paper – Due next Monday 2/8
- Write script/prepare for 1st information and training session for volunteers
    - Content related to disability types, behavior management strategies, communication techniques, and sensory integration approaches
- Continue to create and develop activities, supplies, and equipment needed for stations during the first respite night
    - List the materials, supplies, and equipment that needs to be created and/or purchased for each station
- Create a combined budget for the two respite nights using Excel spreadsheets
    - Church provided me with a budget of $300
- Create additional outcome measures to target key stakeholders
    - Formative post assessment for volunteers (informs changes to program)
    - Formative post assessment for participants/children (informs changes to program)
    - Formative post assessment for volunteers (informs success of program): combined with other formative post assessment for volunteers
- Print materials needed for social skills and bingo stations
- Go to local businesses and organizations in Noblesville and ask to post a flyer advertising the respite program
- Begin researching support groups for caregivers of children with disabilities to disseminate final poster to
- Staff meeting – 2/2 Zoom @ 9
- Safe Sanctuaries Training – Tom @ 2:30 Zoom
- Wednesday meeting with Ally @ 10
- Draft of Background/Introduction for DCE paper – Due Monday 2/1
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Week 5 (Feb 8-Feb 14)

- Write script/prepare content and presentation for first volunteer training session
    - Content related to disability types, behavior management strategies, communication techniques, and sensory integration approaches
- Create detailed schedule for volunteers to follow during 3/6 respite night
- Think about what supplies are needed for 1st respite night
- Write script/prepare content for caregiver education video
    - Provide statistics on children with special needs, explain respite care services, explain the importance of self-care, explain schedule of events during respite night
- Create infographic for caregiver education video
- Collaborate with Director of Family Services regarding the need for childcare at volunteer session - (N/A for first volunteer training session because held via Zoom)
- Staff meeting – 2/9 Zoom @ 9
- Wednesday meeting with Ally @ 10
- Draft of Methods for DCE paper – Due 2/8
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 6 (Feb 15-Feb 21)

- Email Media Specialist infographic for caregiver education video
- Record caregiver education video - record Tuesday, 2/16
- Collaborate with Media Specialist and provide her with recordings of caregiver education video so she can create a full video and post on the church's YouTube channel
- Cut and laminate items for various stations for 3/6 respite night
- Analyze the participants' registration forms and the volunteers' registration forms
    - Highlight the most important information
- Create a separate binder for volunteers and a separate binder for participants, keeping their printed registration forms in these binders for quick access during the respite night in case of an emergency
- Match volunteers up with children based on the volunteers' prior experiences interacting with children with special needs and their comfort levels, and the children's behavioral, medical, sensory, and communicative needs
- Email volunteers that are registered for the 3/6 respite night the Zoom training session link
    - Include the "cheat sheet" of their child and any resources for the training session (cheat sheet, schedule, station list)
    - Sent email on 2/19, 4 days before training session
- Store items, materials, supplies, etc. for the respite night in Educational Resources room
- ***Deadline to register for the first respite night is Thursday, 2/18!!!!!
- Order supplies for 3/6 respite night
- Staff meeting – 2/16 Zoom @ 9
- Family Ministry Meeting - 2/16 @ 11:30
- Wednesday meeting with Ally @ 10
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Week 7 (Feb 22-Feb 28)

- Email educational video to caregivers that registered for the 3/6 respite night
    - Emailed on 2/24 (1.5 weeks away from the 3/6 respite night)
- Recruit church staff members and other ministry volunteers to be "floaters" during the respite night
- Collaborate via email with individuals who expressed interest in volunteering for respite night after the 2/18 registration deadline and 2/23 training session - plan to use them as "floaters" and assist with running stations, cleaning, moving tables/chairs
- Create new registration form for "late registration" volunteers
- Create Google Drive folder to upload resources from DCE, share with site mentors
- Organize supplies and materials located in Educational Resources room to ensure all necessary items are created/purchased for the respite night
- Cut and laminate items for various stations
- Purchase clothing items from Goodwill and food items from Walmart using the church's credit card and money from the $300 budget
- Watch the selected movie for the respite night - Iron Man & Hulk: Heroes United
- Contact Maintenance Supervisor and collaborate with him regarding floor layout, plan, and vision for respite night space
- Provide Maintenance Supervisor with a visual diagram of the floor layout - include number of tables, chairs, location of tables, chairs, stations/activities
- Prepare and practice for volunteer training session
- Staff meeting – 2/23 Zoom @ 9
- 1st informal information and training session for volunteers - 2/23 via Zoom
- Wednesday meeting with Ally @ 10
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday
- Midterm Evaluation with Ally on CORE

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 8 (Mar 1-Mar 7)

- Prepare formative post-assessment tools/outcome measures
    - Make copies of the volunteer and participant exit surveys
- Create sensory bins using shredded paper (use in the Sunshine Sundays classroom)
- Organize printed resources for volunteers (Safe Sanctuaries form, schedule, color coded label key, "cheat sheet")
- Organize materials/supplies for respite night
- Complete a final "run through" with the Media Specialist using the sound booth to practice streaming/projecting the movie, using the sound system, and using the wireless microphone - Alivia on 3/4 @ 12:30
- Email Preschool Director to coordinate receiving supplies and activities for respite night
- Collaborate with site mentors, who are volunteering for the first respite night, to discuss their responsibilities during the respite night
- Create list of responsibilities for each volunteer
- Create list of information and details volunteers must know when they arrive for the tour on respite night
- Update the respite night schedule and list of activities if necessary
- Coordinate use of photo backdrop with Media Specialist
- Create banner for photo backdrop
- Set up photo backdrop purchased and created supplies
- Create and laminate signs for food stations in the kitchen
- Create and laminate signs for activities/stations
- Create a master copy "cheat sheet" for site mentor and I
- Place ~10 Clorox wipes in a Ziploc bag for each volunteer to carry and use during the night
- Email final reminder to volunteers - 2 days away from respite night
    - Include list of general responsibilities for all volunteers
- Begin to set up activities/stations for respite night on the day before
- Begin to set up Sunshine Sundays classroom as the sensory room
- Tape individual post-it notes for each volunteer and participant on the drums
- Take pictures of the set-up after everything is finalized and set-up
- Staff meeting – 3/2 Zoom @ 9
- 1st respite care night on 3/6 - @ 6-9 pm
- Wednesday meeting with Ally @ 10
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 9 (Mar 8-Mar 14)

- Send "Thank You" email to participants (caregivers)
  - Include link to the Qualtrics formative and summative post-assessment based on the Caregiver Burden Scale
  - Include pictures of children
- Send "Thank You" email to 3/6 respite night volunteers
- Forward 3/6 respite night photos to lead pastor, site mentor, and communications specialist
- Begin to contact potential/questionable caregivers and volunteers about 4/3 respite night
- Begin to contact community organizations via email and phone to advertise for the respite program and recruit participants and volunteers (Boys and Girls Club, Special Olympics, nursing homes, YMCA, ABA clinics, pediatric clinics)
- Create/review list of changes to implement for 4/3 respite night
- Convert and organize the data from Qualtrics formative post- and summative assessment for Caregiver Burden Scale into Excel spreadsheet
- Convert and organize the data from the volunteers' formative post-assessment into Excel spreadsheet
- Analyze the caregivers' formative post-assessment results for 3/6 respite night
- Record video discussing purpose of respite nights and results of 3/6 respite night
  - Video presented as Stewardship Moment, played for entire congregation at 3/14 services
  - Method of disseminating project to stakeholders
- Finalize Methods section of paper
- Email 4/3 respite night volunteers to determine if childcare needed for second volunteer training session
- Collaborate with Director of Family Services regarding the need for childcare at volunteer training session
- Staff meeting – 3/9 Zoom @ 9
- Wednesday meeting with Ally @ 10
- Finalize Methods section based on UIndy faculty mentor's feedback – due 3/8
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 10 (Mar 15-Mar 21)

- Write script/prepare for 2nd information and training session for volunteers
  - Content related to disability types, behavior management strategies, communication techniques, and sensory integration approaches
  - Tour of church and rooms being utilized during 4/3 respite night
- Create stations and activities for 4/3 respite night
- Create detailed schedule for volunteers to follow during 4/3 respite night
- Update list of supplies, equipment, materials needed for 4/3 respite night
- Order supplies, equipment, material needed for 4/3 respite night
- As new participants (caregivers) and volunteers register, analyze the participants' registration forms and the volunteers' registration forms
  - Highlight the most important information
- Update separate binders for volunteers and participants, keeping their printed registration forms in these binders for quick access during the respite night in case of an emergency
- Match volunteers up with children based on the volunteers' prior experiences interacting with children with special needs and their comfort levels, and the children's behavioral, medical, sensory, and communicative needs
- Email volunteers that are registered for the 4/3 respite night the training session link
  - Include the "cheat sheet" of their child and any resources for the training session (cheat sheet, schedule, station list)
  - Sent email on 2/19, 4 days before training session
- Store items, materials, supplies, etc. for the 4/3 respite night in Educational Resources room
- ****Deadline to register for respite night is Thurs Mar 18!!!!!
- Write Results section of paper
- Staff meeting – 3/16 Zoom @ 9
- Family Ministry Meeting - 3/16 @ 11:30
- Wednesday meeting with Ally @ 10
- Draft of Results for DCE paper – Due 3/20
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 11 (Mar 22-Mar 28)

- Prepare and practice for volunteer training session on 3/23
- Email educational video to caregivers that registered for the 4/3 respite night
    - Emailed on 3/24 (1.5 weeks away from 4/3 respite night)
- Create list of information and details volunteers must know when giving volunteers the tour during the volunteer training session on 3/23
- Create stations and activities for 4/3 respite night
- Collaborate via email with individuals who expressed interest in volunteering for respite night after the 2/18 registration deadline and 2/23 training session - plan to use them as "floaters" and assist with running stations, cleaning, moving tables/chairs
- Cut and laminate items for various stations for 4/3 respite night
- Organize supplies and materials located in Educational Resources room to ensure all necessary items are created/purchased for the 4/3 respite night
- Purchase clothing items from Goodwill and food items from Walmart using the church's credit card and money from the $300 budget
- Watch the selected movie for the respite night
- Contact Maintenance Supervisor and collaborate with him regarding floor layout, plan, and vision for the 4/3 respite night space
- Provide Maintenance Supervisor with a visual diagram of the floor layout
    - Include number of tables, chairs, location of tables, chairs, stations/activities
- Begin writing Discussion & Implications for Practice of DCE paper
- Write Dissemination Plan for paper
- Prepare for Easter Sunday
- Staff meeting – 3/23 Zoom @ 9
- 2nd informal information and training session for volunteers - 3/23 in the Vine
- Wednesday meeting with Ally @ 10
- Write Implications section of paper
- Finalize Dissemination Plan – Due 3/27
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 12 (Mar 29-Apr 4) Easter Weekend

- Create sensory bins using shredded paper (use in the Sunshine Sundays classroom)
- Organize printed resources for volunteers (Safe Sanctuaries form, schedule, color coded label key, "cheat sheet")
- Organize materials/supplies for 4/3 respite night
- Complete a final "run through" with the Media Specialist using the sound booth to practice streaming/projecting the movie, using the sound system, and using the wireless microphone
    - Completed on 3/31 @ 12:30
- Email Preschool Director to coordinate receiving supplies and activities for respite night
- Collaborate with site mentors, who are volunteering for the first respite night, to discuss their responsibilities during the respite night
- Create list of responsibilities for each volunteer
- Update the 4/3 respite night schedule and list of activities if necessary
- Coordinate use of photo backdrop with Media Specialist
- Create banner for photo backdrop
- Set up photo backdrop purchased and created supplies
- Create and laminate signs for food stations in the kitchen
- Create and laminate signs for activities/stations
- Create a master copy "cheat sheet" for site mentor and I
- Place ~10 Clorox wipes in a Ziploc bag for each volunteer to carry and use during the night
- Email final reminder to volunteers - 2 days away from respite night
    - Include list of general responsibilities for all volunteers
- Begin to set up activities/stations for respite night on the day before
- Begin to set up Sunshine Sundays classroom as the sensory room
- Tape individual post-it notes for each volunteer and participant on the drums
- Take pictures of the set-up after everything is finalized and set-up
- Begin writing Final Results of DCE paper
- Continue writing Discussion & Implications for Practice of DCE paper
- Wednesday meeting with Ally @ 10
- Staff meeting – 3/30 Zoom @ 9
- 2nd respite care night on 4/3 - @ 6-9 pm
- Discussion & Implications for Practice for DCE paper – Due 4/2
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Week 13 (Apr 5-Apr 11)

- Send "Thank You" email to caregivers
  - Include link to the Qualtrics formative and summative post-assessment based on the Caregiver Burden Scale
  - Include pictures of children
- Forward 4/3 respite night photos to lead pastor, site mentor, and communications specialist
- Clean up and organize activities, supplies, and rooms utilized for 4/3 respite night
- Create/review list of changes to implement for 4/3 respite night
- Convert and organize the data from Qualtrics formative post- and summative assessment for Caregiver Burden Scale into Excel spreadsheet
- Convert and organize the data from the volunteers' formative post-assessment into Excel spreadsheet
- Analyze caregivers' formative post-assessment results for 4/3 respite night
- Record video discussing purpose of respite nights and results of 4/3 respite night
  - Video presented as Stewardship Moment, played for entire congregation at 4/25 services
  - Method of disseminating project to stakeholders
- Continue communicating with the Autism Society of Indiana to discuss possible partnership with NFUMC for future respite nights
- Organize and clean Educational Resources Room with site mentor
- Analyze formative post- and summative assessment data for 4/3 respite night
- Write "Thank you" cards and mail them to the volunteers for 4/3 respite night
- Continue discussing sustainability of project with site mentors
- Continue writing Final Results of DCE paper
- Create presentation for site mentors
- Update shared Google Drive for site mentors
- Staff meeting – 4/6 Zoom @ 9
- Wednesday meeting with Ally @ 10
- Final Results of DCE paper – due 4/9
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Week 14 (Apr 12-Apr 16)

- Present final presentation/disseminate results to DCE site
- Update shared Google Drive for site mentors
- Record video discussing results of 4/3 respite night and future of respite program
  - Video presented as Stewardship Moment, played for entire congregation at 4/25 services
  - Method of disseminating project to stakeholders
- Staff meeting – 4/13 Zoom @ 9
- Wednesday meeting with Ally @ 10
- Luncheon with entire church staff – 4/14 @ 11:30
- Draft of Discussion & Abstract section of DCE paper – due 4/12
- Final CORE evaluation with Ally on DCE
- Weekly Forum – Initial due Tuesday, 3 peer responses due Friday

Appendix B. 14-week timeline that outlines my process for achieving my goals and objectives and carrying out the DCE project.

Appendix C

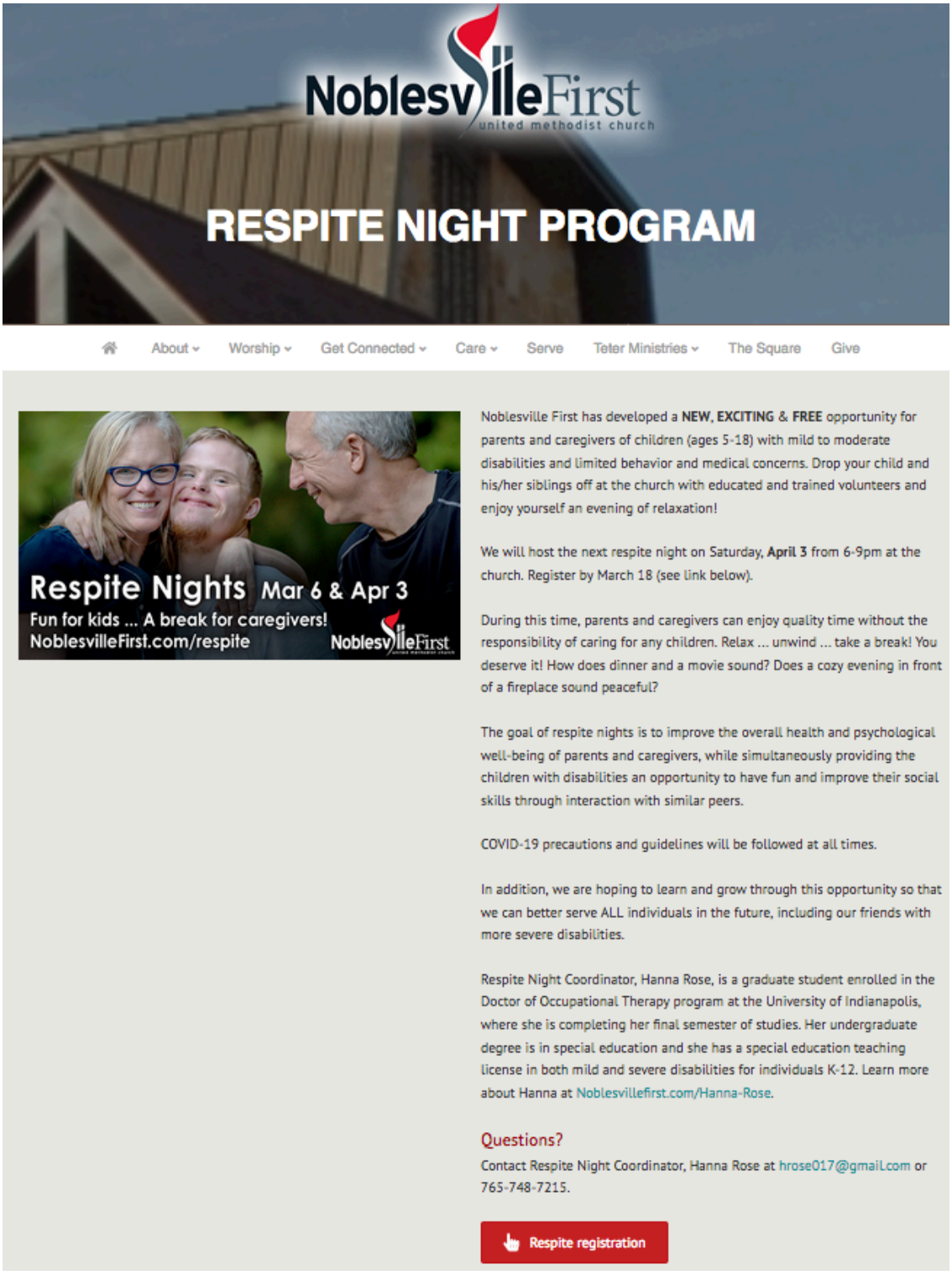
Microsoft Excel® spreadsheet

		Item	Quantity	Price Each	With Tax	Shipping	Respite Night	Link
2	Autism Products	Children's Headphones	2	$5.49	No tax	$10.00		https://www.autism-products.com/product/califone-autism-hearing-safe-protectors-for-children-hs40-26db/
3		Adult Headphones	2	$8.99				https://www.autism-products.com/product/califone-autism-hearing-safe-protectors-hs50-28db/
4		Red T Chew w/o Bumps	2	$6.95				https://www.autism-products.com/product/chewy-tube-red-1-2-inch-diameter/
5		Red Key Chew w/ Bumps	2	$5.95				https://www.autism-products.com/product/red-knobby-super-chew/
6				Total = $54.76 + ~$10 shipping				
7								
8	Amazon	Fidget Spinners (pack of 5)	1	$7.99	$8.55	$0 (Prime)		kindergarten%EF%BC%88XS/dp/B072F7ZDXR/ref=sr_1_26?crid=2FWE9THA6E9JI&dchild=1&keywords=single+fidge
9		Wiggle Seat	1	$17.99	$19.25	$0 (Prime)		WVyPUExMlgzOVgzVDVDTkE0JmVuY3J5cHRlZElkPUEwNjYyNzQ2MTVKSFhXSjlMOUtaRCZlbmNyeXB0ZWRBZElk
10		A-Z Binder Tabs	2	$5.46	$11.68	$0 (Prime)		UTF8&psc=1
11		Blank White Adhesive Name Tag Labels (80)	1	$6.84	$7.32	$0 (Prime)		https://www.amazon.com/dp/B004ISI35Y/ref=twister_B07YWQ1S1Q?_encoding=UTF8&psc=1
12		Colored Stickers (10 Colors, 1260 Stickers)	1	$6.05	$6.47	$0 (Prime)		Printer/dp/B016LDXWAY/ref=sr_1_18?crid=3M33M416KJC06&dchild=1&keywords=garage+sale+stickers&qid=161163
13		Spiderman Bean Bag Toss	1	$12.99	$13.90	$0 (Prime)		Decorations/dp/B089M3JSY9/ref=sr_1_21_sspa?dchild=1&keywords=Superhero+Banners&qid=1611620982&sr=8-21-
14		Superhero Stickers	1	$6.95	$7.44	$0 (Prime)		Stickers/dp/B07K9156GB/ref=sr_1_3?crid=13UZ5X9EEE8R&dchild=1&keywords=disney+princess+stickers&qid=1613
15		Disney Princess Stickers	1	$3.89	$4.16	$0 (Prime)		Stickers/dp/B07K9156GB/ref=sr_1_4?crid=37AB261O4L6K8&dchild=1&keywords=disney+princess+stickers&qid=1613
16		Superhero Capes and Masks Set (24 count)	1	$38.99	$41.72	$0 (Prime)		https://www.amazon.com/gp/product/B07W6F724Z/ref=ox_sc_act_title_1?smid=A38HVLJEE8QGYF&psc=1
17				Total =	$120.49			
18								
19	Oriental Trading	Superhero Stickers (1 roll, 100 pieces)	1	$2.88		Free		13626681.fltr?recommendation=Customers%20Also%20Bought&searchTarget=&PdpRedirect=REDIRECT&keyword=
20		Tropical Sea Life Stickers (1 roll, 100 pieces)	1	$2.89		Free		https://www.orientaltrading.com/tropical-sea-life-sticker-rolls-a2-34_1825.fltr?source=shoppingcart
21				Total = $6.17				
22								
23	Walmart	Mini Individual Packed Pretzels (10 count)	5	$3.83		$19.15		Ct/10293731
24		SkinnyPop Variety Pack Popcorn (14 bags - 7 regular, 7 cheddar)	4	$7.47		$29.88		https://www.walmart.com/ip/SkinnyPop-Popcorn-Variety-Snack-Pack-Cheddar-and-Original-14ct-5oz-Bags/598319049
25		Great Value Original Applesauce (6 cups)	9	$1.43		$12.87		https://www.walmart.com/ip/Great-Value-Original-Applesauce-4-oz-6-count/14562672
26		Great Value Mozzarella String Cheese (12 count)	4	$2.84		$11.36		oz/364923224
27		Great Value Purified Drinking Water (16.9 oz, 24 bottles) -already have 36	1	$2.68		$2.68		
28		Great Value Purified Drinking Water (16.9 oz, 40 bottles)	1	$3.98		$3.98		
29		Snyder's Gluten Free Pretzel Sticks (8 count)	1	$9.12		$9.12		Count/175669510
30		2-Liter Pop Bottles	3	$0.72		$2.31		
31				Total =		$91.35		
32								
33	Goodwill	5 year old tshirt boy						
34		5 year old boy pants						
35		Men's sweatpants - L, M						
36		Adult tshirt - M, L		Total =		$13.86		
37								
38	Dollar Tree	Jump Rope	2	$1		$2		
39		Fly Swatter	1	$1		$1		
40		Bowling Ball	1	$1		$1		
41		2-Liter Pop Bottle	2	$1		$2		
42				Total =		$4.40		
43								
44				Grand Total =		$303.03		
45								
46								

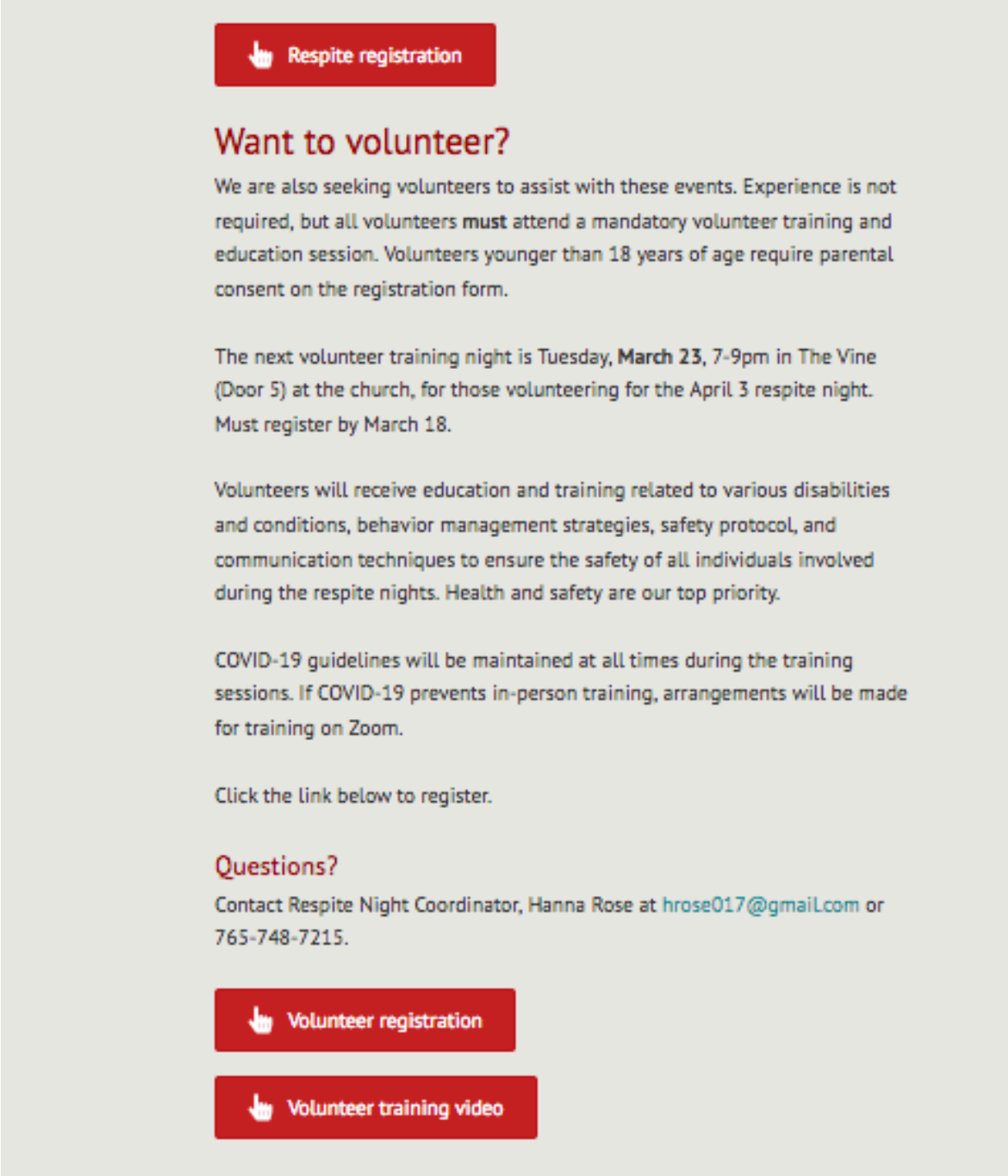
Appendix C. Microsoft Excel® spreadsheet of the $300 budget NFUMC provided me for the two respite nights.

Appendix D

Respite Night Page on Church Website

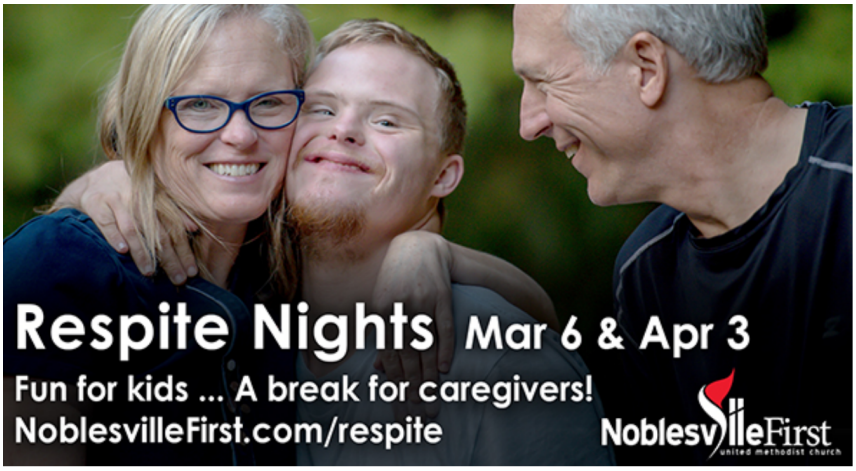


Appendix D. Respite Night page created on NFUMC's website.



Appendix D. Respite Night page created on NFUMC's website.

Appendix E
Respite Night Flyer



Noblesville First United Methodist Church

and

NFUMC is holding a **NEW, EXCITING,** and **FREE** event for caregivers/parents of **children with mild to moderate disabilities and limited behavior and medical concerns (ages 5-18)!** We're in the beginning stages of developing a respite program and want to ensure success and safety for all individuals involved as we continue to develop this program. We're hoping to learn and grow from this opportunity so we can better serve ALL individuals in the future, including our friends with severe disabilities.

On **3/6/2021 and 4/3/2021** from **6-9pm,** we will be hosting respite nights, where caregivers and parents can drop off their child at the church with educated and trained volunteers before enjoying a relaxing night to themselves. **Siblings are welcome!** If you are a caregiver or parent, now is your time to enjoy quality time and peace and quiet. Relax...unwind...take a break! You deserve it!

The overall goal of respite nights is to improve parents' and caregivers' overall health and psychological well-being, while simultaneously providing their children with disabilities opportunities to improve their social skills through interaction with similar peers. We recognize the stresses many caregivers and parents face when caring for a child with a disability and want to provide some relief, especially during these unprecedented times. **COVID-19 precautions and guidelines will be followed at all times.**

We are seeking volunteers and participants for this event. If you are interested in volunteering, would like to register a child for this event, or would like additional information, please visit our church website here, NoblesvilleFirst.com/respite. You may also contact Family Ministry Intern, Hanna Rose, at hrose017@gmail.com.

Volunteers and participants, REGISTER HERE!!

SCAN ME

https://www.instagram.com/noblesvillefirst/

https://www.facebook.com/NoblesvilleFirstUmc

https://twitter.com/4NFUMC

powered by PIKTOCHART

Appendix E. Respite Night flyer used for advertisement to various community organizations.

Appendix F

Newspaper Articles

Announcements
WEDDINGS
ANNIVERSARIES
BIRTHS
ENGAGEMENTS

The TIMES
Hamilton County's Only Daily Newspaper

News Sports Obituaries Opinion Page Columnists E-Edition Where's Will

First UMC intern creates much needed respite care

By Betsy Reason, Editor

Tuesday, March 16, 2021 4:00 AM

A desire to live, work and play in Hamilton County and a passion for helping children with special needs has brought a special education teacher and graduate student to our area to create a respite (short-term care) program for caregivers.

Hanna Rose, who moved to Fishers over the winter to complete her final capstone project to earn her Doctorate in Occupational Therapy, is a family ministry intern at Noblesville First United Methodist, where she has created a pilot Respite Night.

Caregivers of children ages 5-18 with mild to moderate disabilities and limited behavior and medical concerns can drop off your child or siblings at the church's Respite Night, from 6 p.m. to 9 p.m. April 3, with registration deadline March 18.

While developing the respite program helps fulfill Rose's requirements for her May graduation, she said designing and implementing the program paired well with Noblesville First UMC's more than 30-year-old Sunshine Friends outreach ministry and Sunday ministry that serve individuals with special needs.

When she arrived, the church didn't have a ministry for caregivers. Rose hopes that the respite program that she created will take away some of the caregivers' burden, anxiety and stress.

"The overall goal of the respite program is to improve the overall health and psychological well-being of parents and caregivers, while simultaneously providing the children with special needs an opportunity to have fun and improve their social skills, gross motor skills and fine-motor skills through interaction with similar peers and engagement in activities," Rose said.

It's the second of two Respite Nights that she created in her role as the church's family ministry intern.

The first Respite Night was March 6. "We have had great responses," Rose said. There were seven children and 12 volunteers who participated. For the April 3 Respite Night, there are already 18 children and seven volunteers registered. "We almost tripled our numbers, which shows the great need to respite care services in the community," Rose said. "Due to the increase in numbers, we could greatly use more volunteers." (Training is set for 7 to 9 p.m. March 23 at the church.)

Volunteers can act as a "buddy" to a child with special needs and engage in a variety of stations with them throughout the night or act as a "floater" and assist with cleaning equipment and supplies, moving furniture and increasing engagement with the children, she said.

"The more volunteers we have, the more I can appropriately match children with volunteers and ensure a 1:1 ratio," Rose said.

About 71 percent of the participating registered caregivers experience a "moderate to severe" burden, while the remaining 29 percent experience a "mild to moderate" burden, according to a survey that she had caregivers to complete when registering for the program.

Rose said these statistics, in addition to numerous responses from caregivers seeking such a program, justify the need for the creation of the Respite Night here in Hamilton County.

"Multiple caregivers also made comments about how last Saturday's (March 6) Respite Night was the first time they had been out together as a couple in over a year, how the event 'lifted their spirits' and how they would benefit from continued respite services," she said.

The creation of the respite program came after Rose contacted the First UMC and conducted multiple needs assessments, which were to identify needs existing in Noblesville and the church community. A respite program designed for caregivers of children with special needs was a recurring theme by all church staff, she said.

A Selma, Ind., native, growing up, Rose, 24, was passionate about children with special needs. Her senior year at Wapahani High School, she was a cadet teacher and volunteered in a self-contained special education classroom. She observed the school occupational therapist working with a student who had poor fine-motor skills, which made it difficult for the child to zip his own coat. As time progressed, she watched the occupational therapist work with the child to increase his independence to zip his coat, with the child making progress each therapy session. "Finally, the child was able to zip his coat independently and the joy on his face was something I had not experienced before," she recalled. "...I knew then that I wanted to become an occupational therapist and assist others in increasing their independence in daily activities and improving their functional skills." She chose occupational therapy because of the "holistic" approach and focus on individual needs.

Creating the respite program and recruiting volunteers for the program are among her many roles as an intern. During the Sunday family worship at First UMC, she acts as the online host and engages with online viewers about the sermon. On Sunday mornings, she also operates the church's Exit 11 program, which is a Biblical teaching and lesson for young children. She also assists with various ministries within the church, including Sunshine Friends.

Rose's capstone project and internship with First UMC ends on April 16, and she will graduate from University of Indianapolis in May with a doctorate of occupational therapy (She already earned a bachelor's degree in special education and is a licensed special education teacher for students with mild and severe disabilities in grades K-12). She plans to take her licensure board exam and become a registered occupational therapist shortly after graduation and work in a skilled nursing facility, "helping to improve older adults' quality of life and independence in activities of daily living."

While she moved to Hamilton County to complete her grad school project, she also moved here because, she said, "I knew this was the area I wanted to live in and attempt to pursue a career in after graduating."

She wants to live, work and play in Hamilton County. "During my free time, I enjoy running, hiking, playing with my cat, spending time with friends and family, playing board games and traveling," Rose said.

After the next pilot Respite Night on April 3, she expects the program to continue.

Rose said, "The church has demonstrated tremendous support through the development of these Respite Nights and is working diligently to continue implementing Respite Nights to serve families of children with special needs."

For information, to sign up for Respite Night or to take training to volunteer, contact Hanna Rose at hrose017@gmail.com or call the church at 317-773-2500.

-Contact Betsy Reason at betsy@thetimes24-7.com.

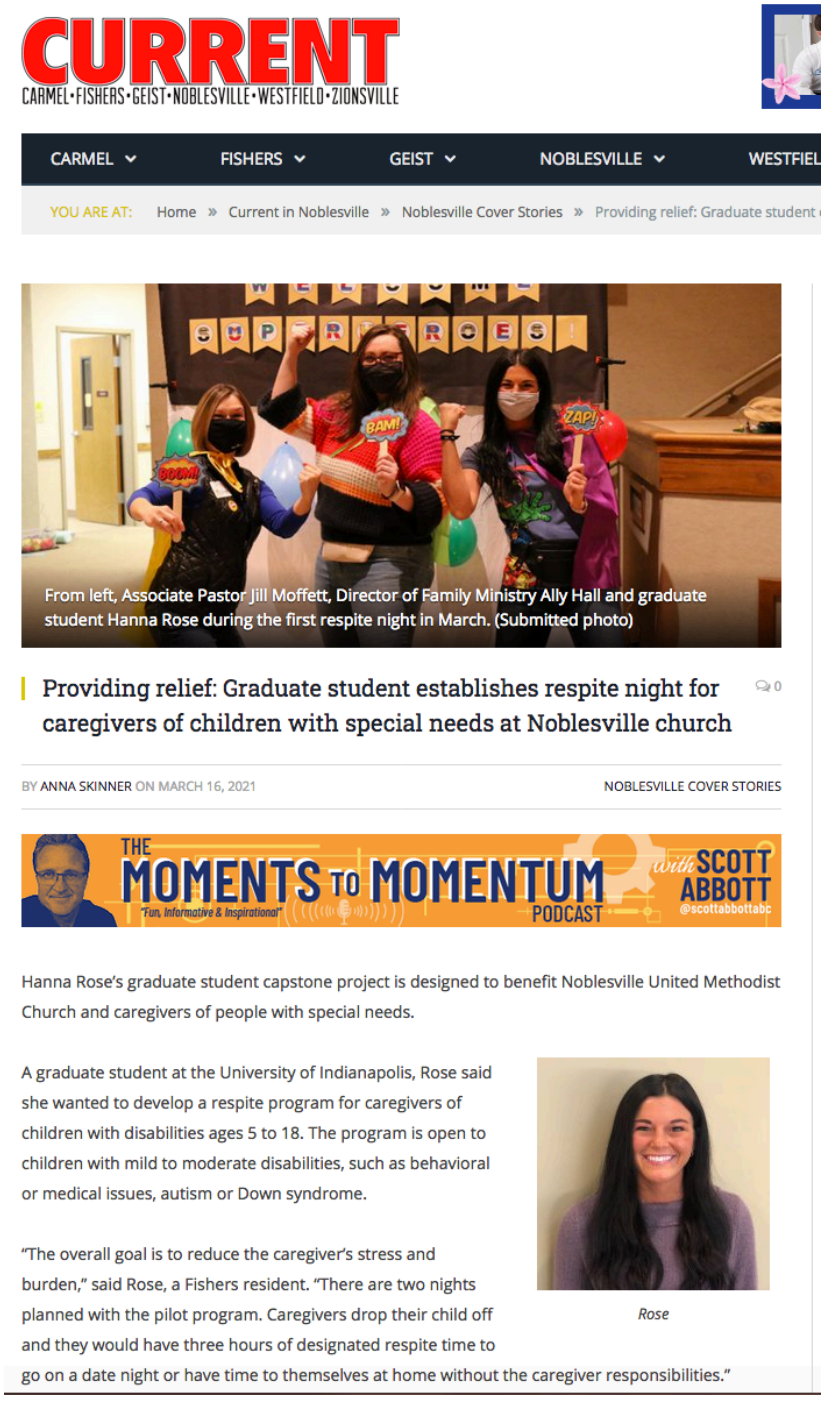
Want MORE?

Caregivers of children ages 5-18 with mild to moderate disabilities and limited behavior and medical concerns can drop off your child or siblings at a pilot Respite Night at Noblesville First United Methodist Church, 2051 Monument St. It's 6 p.m. to 9 p.m. April 3, with registration by March 18. During this time, parents and caregivers can enjoy their own quality time while their children are enjoying activities at the church. Volunteers are also sought and will be trained 7 to 9 p.m. March 23. It's the second of two Respite Nights. For information, contact Hanna Rose at hrose017@gmail.com or call the church at 317-773-2500.

Figure 1. The Times Newspaper article covering the pilot respite care program. https://thetimes24-7.com/Content/Columnists/Columnists/Article/First-UMC-intern-creates-much-needed-respite-care/13/163/69506

Appendix F

Newspaper Articles



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YOU ARE AT: Home » Current in Noblesville » Noblesville Cover Stories » Providing relief: Graduate student

From left, Associate Pastor Jill Moffett, Director of Family Ministry Ally Hall and graduate student Hanna Rose during the first respite night in March. (Submitted photo)

Providing relief: Graduate student establishes respite night for caregivers of children with special needs at Noblesville church

0

BY ANNA SKINNER ON MARCH 16, 2021

NOBLESVILLE COVER STORIES

Hanna Rose's graduate student capstone project is designed to benefit Noblesville United Methodist Church and caregivers of people with special needs.

A graduate student at the University of Indianapolis, Rose said she wanted to develop a respite program for caregivers of children with disabilities ages 5 to 18. The program is open to children with mild to moderate disabilities, such as behavioral or medical issues, autism or Down syndrome.

Rose

"The overall goal is to reduce the caregiver's stress and burden," said Rose, a Fishers resident. "There are two nights planned with the pilot program. Caregivers drop their child off and they would have three hours of designated respite time to go on a date night or have time to themselves at home without the caregiver responsibilities."

Figure 2. The Current Newspaper article covering the pilot respite care program. https://www.youarecurrent.com/2021/03/16/providing-relief-graduate-student-establishes-respite-night-for-caregivers-of-children-with-special-needs-at-noblesville-church/

Appendix F
Newspaper Articles

The first respite night was March 6. The second is planned for 6 to 9 p.m. April 3. Siblings can attend. The program is open to families throughout Hamilton County. Rose said she did a needs assessment that showed more than 80 percent of caregivers of people with disabilities experienced moderate to severe stress. The assessment also showed there was not a respite program in the Noblesville area.

"I identified that some larger churches have had a respite program and that there wasn't a church in the immediate surrounding area that had a respite program," Rose said.

During the respite night, children with disabilities spend time with trained volunteers playing games and doing other fun activities for three hours.

"There are a lot of stations during the respite night targeting fine motor skills, gross motor skills and social skills. I wanted to incorporate aspects of occupational therapy in the stations we set up," said Rose, who is studying to be an occupational therapist.

One of the respite night stations was a handheld music playing area, which consisted of a variety of musical instruments. The children created beats with the instruments and volunteers tried to repeat the beats back to them, and vice versa.

NUMC Pastor Jerry Rairdon said the goal is to continue offering respite nights even after Rose completes her capstone project.

"The goal is to get this started to identify that there's a definite need for it, and hopefully establish enough volunteers that it can be carried on," Rairdon said. "It falls in line very much with our vision. Sometimes, children and adults with special needs get holed away and are not seen as part of the community, and our goal is to try to get to the point where they're embraced by the community and seen as a benefit to the community."

Rairdon said NUMC has had a program for more than 30 years that meets once a month for adults with special needs. Also, NUMC has conducted a Sunday school class for adults or children with special needs for the past five years.

Figure 2. The Current Newspaper article covering the pilot respite care program. https://www.youarecurrent.com/2021/03/16/providing-relief-graduate-student-establishes-respite-night-for-caregivers-of-children-with-special-needs-at-noblesville-church/

Appendix F

Newspaper Articles

One of the respite night stations was a physical activity area consisting of a large parachute that the children shook up and down while trying to keep inflated balls on top of the parachute. The children counted how many times they could shake the parachute before the balls fell off. (Submitted photos)

"It's a small group, five to six people at a time, but it's been very valuable to those in the church, and it's been a way to draw others," Rairdon said of the Sunday school program. "It's something we've experienced with church members that have kids with special needs, just knowing the challenge they have. It's a constant stress all the time, and this is a real opportunity to give them a break once a month. It fits very much with what we're doing."

When she graduates, Rose wants to work in outpatient pediatrics or in a skilled nursing facility as an occupational therapist.

Caregivers wanting to register their child with special needs for the April 3 respite night must do so by March 18. The program is free. To register, email Rose at hrose017@gmail.com.

Figure 2. The Current Newspaper article covering the pilot respite care program. https://www.youarecurrent.com/2021/03/16/providing-relief-graduate-student-establishes-respite-night-for-caregivers-of-children-with-special-needs-at-noblesville-church/

Appendix G
Registration Forms

Medical Release Form

Volunteer Information

Name: _____ DOB: _____

Address: _____ City/State/Zip: _____

Email: _____ Phone: _____

***Parent Information:** (if applicable)

Mother's Name: _____ Phone: _____

Father's Name: _____ Phone: _____

Permission by Volunteer

I, _____, am choosing to volunteer with the NFUMC's respite night event.

_____ _____
Volunteer Signature Date

***Permission by Parent:** (if applicable)
I give my permission for the individual listed above to participate with NFUMC's respite night event.

_____ _____
Parent/Legal Guardian Signature Date

Medical Information

Family Physician: _____ Phone: _____

Allergies (i.e. Penicillin, Poison Ivy, Bee Sting): _____

Date of last Tetnus shot: _____

Any other medical information that would be helpful for us to know:

_____

_____

Consent for Treatment

I (We) hereby give permission and written consent to the hospital selected by NFUMC staff to provide any medical treatment and/or surgical treatment to the individual named above as deemed necessary for the care of any injury or illness.

_____ _____
Volunteer or Parent/Legal Guardian Signature Date

Figure 1. Volunteer registration form.

Medical Insurance Carrier: _____ Policy #: _____

Emergency Contact Other than Above: _____ Phone: _____

Experience

Please describe experiences you have had working or volunteering with individuals with disabilities.

_____

_____

Please list any certifications you may have (i.e. CPR, ABA therapist, nurse, special education teacher).

_____

_____

Using a 5-point rating scale, please rate your level of comfort related to the following situations.
(1-not comfortable, 3-somewhat comfortable, 5-very comfortable)

- Changing a diaper/assisting with toileting 1 2 3 4 5
- Slobber/drooling 1 2 3 4 5
- Redirecting a child who is refusing 1 2 3 4 5
- Assisting a child with feeding 1 2 3 4 5
- Addressing challenging behaviors (biting, hitting, yelling) 1 2 3 4 5
- Overall comfort level interacting with child with special needs 1 2 3 4 5

I acknowledge that I will need to complete a background check, which will be emailed to me.
(Noblesville First UMC will pay this expense.) □ Yes □ No

I am interested in volunteering for the following respite night(s):

- □ March 6th, 6-9pm, at the church
- □ April 3rd, 6-9pm, at the church

I will attend the following mandatory volunteer training sessions:

- □ February 23rd, 7-9pm, on Zoom for March 6th Respite Night
- □ March 23rd, 7-9pm, at the church for April 3rd Respite Night

Figure 1. Volunteer registration form.

Appendix G
Registration Forms

Medical Release Form

Volunteer Information

Name: _____ DOB: _____

Address: _____ City/State/Zip: _____

Email: _____ Phone: _____

***Parent Information:** (if applicable)

Mother's Name: _____ Phone: _____

Father's Name: _____ Phone: _____

Permission by Volunteer

I, _____, am choosing to volunteer with the NFUMC's respite night event.

_____ _____
Volunteer Signature Date

***Permission by Parent:** (if applicable)
I give my permission for the individual listed above to participate with NFUMC's respite night event.

_____ _____
Parent/Legal Guardian Signature Date

Medical Information

Family Physician: _____ Phone: _____

Allergies (i.e. Penicillin, Poison Ivy, Bee Sting): _____

Date of last Tetnus shot: _____

Any other medical information that would be helpful for us to know:

_____

_____

Consent for Treatment

I (We) hereby give permission and written consent to the hospital selected by NFUMC staff to provide any medical treatment and/or surgical treatment to the individual named above as deemed necessary for the care of any injury or illness.

_____ _____
Volunteer or Parent/Legal Guardian Signature Date

Figure 2. Updated volunteer registration form after the registration deadline passed.

Medical Insurance Carrier: _____ Policy #: _____

Emergency Contact Other than Above: _____ Phone: _____

Experience

Please describe experiences you have had working or volunteering with individuals with disabilities.

_____

_____

Please list any certifications you may have (i.e. CPR, ABA therapist, nurse, special education teacher).

_____

_____

Using a 5-point rating scale, please rate your level of comfort related to the following situations.
(1-not comfortable, 3-somewhat comfortable, 5-very comfortable)

- Changing a diaper/assisting with toileting 1 2 3 4 5
- Slobber/drooling 1 2 3 4 5
- Redirecting a child who is refusing 1 2 3 4 5
- Assisting a child with feeding 1 2 3 4 5
- Addressing challenging behaviors (biting, hitting, yelling) 1 2 3 4 5
- Overall comfort level interacting with child with special needs 1 2 3 4 5

I acknowledge that I will need to complete a background check, which will be emailed to me.
(Noblesville First UMC will pay this expense.) □ Yes □ No

I am interested in volunteering for the following respite night(s):

- □ March 6th, 6-9pm, at the church
- □ April 3rd, 6-9pm, at the church

I will watch the online YouTube video because I was unable to attend the mandatory volunteer training session. I will notify Respite Night Coordinator, Hanna Rose, at hrose017@gmail.com once I have completed the training and ask any questions I may have regarding the content or details related to respite night. □ Yes □ No

Link: https://www.youtube.com/watch?v=-YzovKkEoNY&feature=youtu.be

Figure 2. Updated volunteer registration form after the registration deadline passed.

Appendix G
Registration Forms

2021 Noblesville First UMC Respite Night Participant Information Form

Participant/Child Information

Name: _____ Parent/Guardian Name(s):_____

Age:_____ Sex: _____ DOB: _____

Address: _____ Mother's Email: _____

City: _____ State: _____ Zip: _____ Mother's Cell: _____

Father's Email: _____

Father's Cell: _____

Primary disability (be specific): _____

Secondary disability (be specific): _____

Community Staff Agency: _____

Staff Name: _____ Staff Phone: _____

Emergency Contact (other than those listed above):

Name: _____ Emergency Phone: _____

Medical Information

LIST ALL MEDICATIONS:

Does participant:

1. Have dietary needs or a special diet? _____
   Any restrictions to the following foods? Pretzels, popcorn, fruit cups, string cheese YES NO

2. Have allergies? YES NO Describe reaction:
   Epi pen? YES NO _____

3. Have seizures? YES NO Physical reaction during seizure: _____

   Types: _____ Reaction after seizure: _____

   Seizure plan: _____

   Call 911? _____ Treatment? _____ Duration: _____

4. Use an assistive device? YES NO How often: _____ Type? Electric Manual Walker

Figure 3. Caregiver registration form.

Medical Administration

- Will participant take any medications during the respite night? YES NO
- Can participant self-medicate? YES NO
- Any medical precautions/care:

_____

_____

Personal and Community Skills

- Needs assistance with eating/drinking YES NO
- Needs assistance with toileting needs YES NO
- Wears a diaper/pull-up YES NO
- Needs assistance with communication YES NO
- Needs assistance with reading/writing YES NO
- Uses Sign Language YES NO
- Uses a hearing aid/device YES NO
- Wears glasses YES NO
- Precautions in sun, heat, cold environments YES NO
- Needs assistance in orientation to people, places, time YES NO
- Describe how the participant communicates (verbally, iPad, visuals, gestures, etc.):

_____

_____

Social/Behavioral Needs

What type of supervision does the participant require (i.e. close, distant, line-of-sight)?

_____

Participant displays: (please describe)

- Unusual fears or concerns (people, places, etc.)
- Physical or verbal aggression to others
- Physical aggression to self
- Flight risk
- Potential triggers:

_____

_____

Figure 3. Caregiver registration form.

Please rate how often the participant exhibits the behavior described below using the 5-point rating scale (1-never, 3-sometimes, 5-frequently).

- Cooperates with peers 1 2 3 4 5
- Participates effectively in family or group activities 1 2 3 4 5
- Listens to and carries out directions from parents or supervisors 1 2 3 4 5
- Follows family and community rules 1 2 3 4 5
- Asks for help in an appropriate manner 1 2 3 4 5
- Is good at initiating or joining conversation with peers 1 2 3 4 5
- Is sensitive to the feelings of others 1 2 3 4 5
- Shows self-control 1 2 3 4 5
- Takes things that are not his or hers 1 2 3 4 5
- Ignores parents or supervisors 1 2 3 4 5
- Has temper outbursts or tantrums 1 2 3 4 5
- Is physically aggressive 1 2 3 4 5

Please explain any tips or techniques we could use to offer the best possible experience for the participant (food, verbal praise, toys, etc.)

_____

_____

Is there any other information that would enhance or limit the participation for this individual (soothing techniques, sensory breaks, calming strategies)?

_____

_____

Describe your primary concerns for the participant:

_____

_____

Other

I grant permission for participant's picture to be used in media, brochures, or advertisements for NFUMC.
YES NO

In case of medical emergency, I herby grant permission and written consent for the staff and volunteers of NFUMC to obtain medical or surgical treatment for the above-named participant.
YES NO

I have reviewed all of the information on this page and made any necessary corrections.
YES NO

Signature of Parent/Guardian: _____

Date: _____

Figure 3. Caregiver registration form.

Appendix H

Volunteer Training Session Videos

Figure 1. A recording of the first volunteer training session that was converted to a video on the church's YouTube channel. (https://www.youtube.com/watch?v=-YzovKkEoNY)

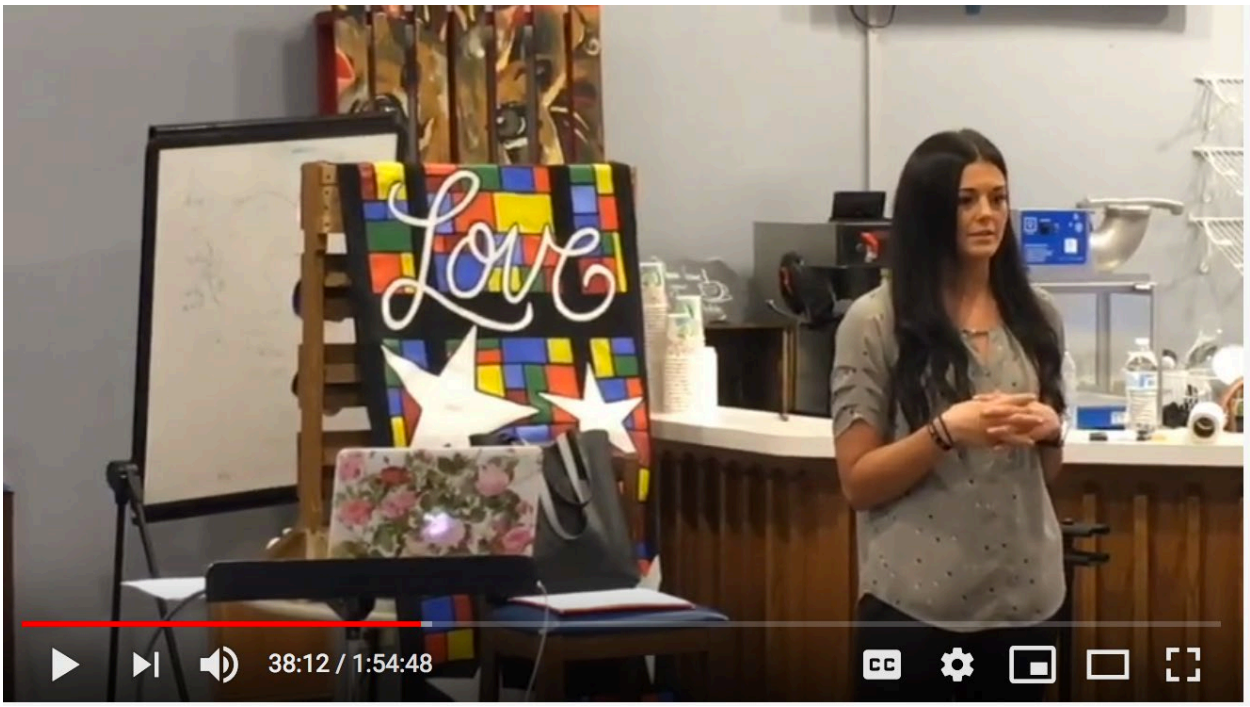


Figure 2. A recording of the second volunteer training session that was converted to a video on the church's YouTube channel. (https://www.youtube.com/watch?v=hBtz_AGsE90)

Appendix I

Child "Cheat Sheet"

Hayley

- Female, age 9
- Parents: Lori
- Primary disability: Nablus Syndrome 8q 2.2.1
- Secondary disability: Autism, ADHD, Speech delay
- Dietary needs: None
  - No restrictions to pretzels, popcorn, applesauce, string cheese
- Medications: None
- Seizures: None
- Allergies: None
- Wears glasses
- Ambulates independently
- Independent with eating/drinking, communication, reading/writing
- Needs assistance with toileting – wears underwear
- Needs assistance with orientation to people, place, time
- Communicates verbally
- Type of supervision required: close
- Triggers:
  - Sometimes doesn't like loud noises – over responsive to sound
- Flight risk
  - May wander off at times
- Rarely asks for help – requires prompting for restroom breaks
- Some difficulty listening and following directions – requires redirection
- Some difficulty interacting with peers
- Very active
  - May get into things she shouldn't
  - Limited attention span
- Doesn't understand concept of stranger danger
- Has pica
  - Puts non-food items in mouth, may sneak items under her mask
- Usually "a very good girl, happy, funny, full of glee"
- Loves Disney princesses, music, ballet (the Nutcracker)
- NO temper tantrums or physical aggression
- Can be photographed? –yes

Appendix I. Example of a "cheat sheet" each volunteer was given for the child(ren) they were matched with, including the child's medical, behavioral, communicative, and sensory needs.

Appendix J

Caregiver Information

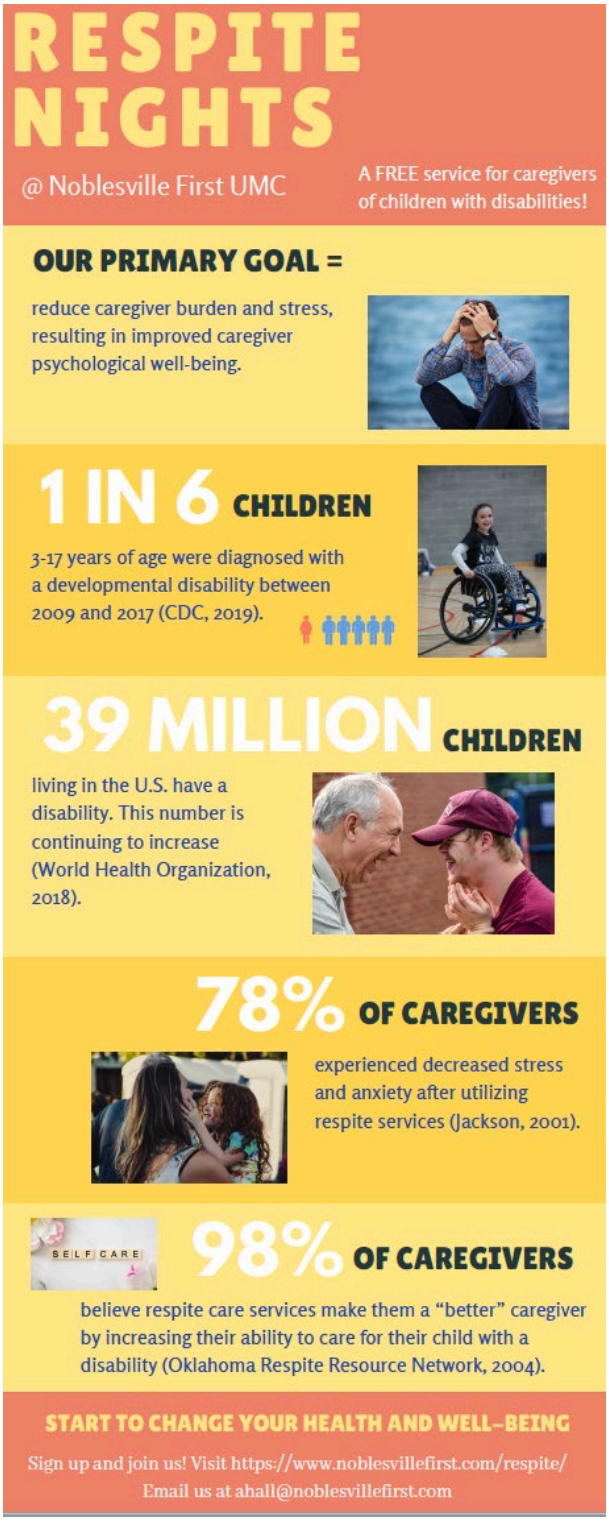


Figure 1. Caregiver infographic including statistics on children with disabilities and respite care services.

Appendix J

Caregiver Information

Figure 2. Educational video emailed to caregivers prior to each respite night that discussed the importance of participating in respite care services, how respite care services can benefit them as caregivers, and the importance of incorporating respite care services into a monthly routine to establish healthy habits. (https://www.youtube.com/watch?v=naG1IMRf9_w)

Appendix K

First Respite Night Volunteer Final Reminder Email

Good morning, 3/6 Respite Night volunteers!

I am very excited to have you all volunteer for the respite night on 3/6 at Noblesville First United Methodist Church! I wanted to send a few final reminders, as we are just TWO days away from the special event!

Final reminders:

- Please arrive at 5:30pm on 3/6 to receive a tour and final details of the event.
- Park and enter through Door 7.
- The church's address is 2051 Monument St. Noblesville, IN 46060.
- The large main room we will be in is called Celebration Hall.
- Items to bring:
  - Pocket hand sanitizer (if you have it)
  - Mask (surgical masks will be provided)
  - Snacks will be provided but you may choose to pack a dinner
  - Wear tennis shoes and jeans with pockets
  - A smile on your face..under your mask! (:
- Physical/hard copies will be provided of:
  - "Cheat sheet" for each child you have been matched with (if you have been matched with a child)
  - Schedule/list of stations

Responsibilities for the night will include:

- Act as a "buddy" to each child you have been matched with (if you have been matched).
  - Floating around various stations
  - Bathroom breaks
  - Washing hands
  - Eating the snack/meal
  - Watching the movie
  - Filling out the exit survey (both yours and the child's)
- Assist with the cleaning of activities and stations using Clorox wipes and Lysol.
- Act as a "floater" and sit in the sensory/quiet room to assist children in calming down and deescalating when they have become overstimulated.
- Act as a "floater" and run/lead various stations in Celebration Hall (explain instructions of the station, interact with children, clean supplies of station).
- Act as a "floater" and assist children in completing their exit survey.
- Move chairs from Marilyn's music station on the right side of Celebration Hall to the left side of Celebration Hall where we will eat the meal.
- Clear activities off of the tables on the left side of Celebration Hall so we can use those tables for the meal.
- Clear stations, activities, and toys from the floor on the left side of the room to prevent distractions during the movie. We will watch the movie after the meal.
- Use Clorox wipes to disinfect tables and chairs before we eat.
- During the last 15 minutes of the event, move activities and equipment to the room located in the far back left of Celebration Hall. (I will show you where this is located during the tour – called the Vine).
- Move additional tables out of Wesley Hall so we can use them for the meal. (I will show you where this is located during the tour).
- Ensure all trash is thrown away after the meal.
- Assist another volunteer in taking their child to the bathroom to ensure we are abiding by the "2-person rule." (Crack the bathroom door and stand halfway in the bathroom).
- Follow COVID-19 precautions at all times.

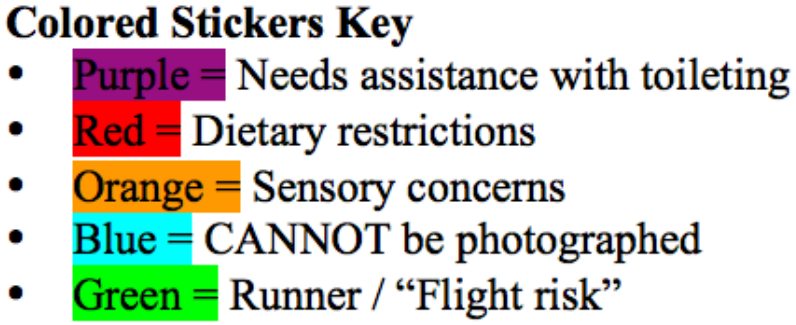
If you would like to review any information from the training session held last Tuesday, 2/23, here is the link to the recorded video on the church's YouTube channel: https://www.youtube.com/watch?v=-YzovKkEoNY&feature=youtu.be

I look forward to seeing you all this weekend! Thank you again for volunteering your time and energy. This program would NOT be possible without YOU!

Appendix K. Email sent to volunteers prior to the first respite night, including final reminders and responsibilities.

Appendix L

Child Name Tag Colored Sticker Key



Appendix L. Key indicating what each colored sticker meant on the children's nametags.

Appendix M

Respite Night Schedules

3/6 Respite Night Schedule

5:30 (volunteer arrival through Door 7, sign-in, tour, name tag, superhero cape)

5:45-6:00 (children arrive, caregiver sign-in, name tag, superhero cape/sticker)

6:00-7:15 (free to float around stations, maintain 6 ft. distance)

- Dancing to music played on CD player
  - Freeze dance
  - Simon Says game
  - Dance ribbons
- Drum set playing with Marilyn
- Handheld music playing instruments
- Quiet room (bean bags, swing, exercise balls, sensory bins) – located down hall, notify Hanna
  - Headphones, fidget spinners, chew tools located here
- Yoga station – walk like an animal, yoga poses
- Physical activity
  - Jumping over pool noodles
  - Hula hoop
  - Playground balls - roll, bounce, pass
  - Twister
- Large/outdoor type games
  - Bean bag toss
  - Tic-tac-toe lawn game
  - Ring toss
  - Throwing parachute men
- Game station
  - Connect Four
  - Trouble
  - Jenga
- Basketball
- Parachute – goal is to keep bean bag/ball in the middle while tossing it in air
- Bingo – can use pictures or words (depends on child's ability level)
- Craft – create your own shield using stickers, markers, crayons
- Building station
  - Legos, plastic stacking blocks, magnetic tiles
- Social skills station
  - Games and activities to help improve their social skills
- Colorful square tiles
- Photo booth – get your picture taken in front of the superhero sign!

7:15-7:20 (wash hands in kitchen, walk through snack line)

7:20-7:45 (begin movie, eat snack and child's prepared meal at table)

7:45-8:45 (watch movie seated on floor or at table)

8:45-9:00 (prepare for dismissal - hand sanitizer for children, coats, volunteers and children each complete exit form)

9:00 (volunteer and caregiver sign-out)

Figure 1. Schedule of the first respite night.

Appendix M

Respite Night Schedules

4/3 Respite Night Schedule

5:40 (volunteer arrival through Door 7, sign-in, name tag, Hawaiian lei/sticker)

5:45-6:00 (children arrive, caregiver sign-in, name tag, Hawaiian lei/sticker)

6:00-7:15 (free to float around stations, check playground schedule)

- Outside playground
- Dancing to music played on CD player – Freeze Dance, Simon Says game, dance ribbons
- Drum set playing with Austyn
- Handheld music playing instruments
- Quiet room (bean bags, swing, exercise balls, sensory bins) – located down hall, notify Hanna
  - Headphones, fidget spinners, chew tools located here
- Yoga station – move like an animal, yoga poses
- Workout station
- Bowling, Basketball
- Indoor hockey, Balloon tennis
- Obstacle course – jump over pool noodles, hula hoops
- Magic Cup – find which cup the object is hidden under
- Playground balls - roll, bounce, pass, kick
- Twister, Limbo, Jump rope
- Large/outdoor type games
  - Bean bag toss
  - Tic-tac-toe lawn game
  - Ring toss
  - Throwing parachute men

- Game station
  - Connect Four, Trouble, Jenga, Ping Pong Pan
- Parachute – goal is to keep bean bag/ball in the middle while tossing it in air
- Bingo – can use pictures or words (depends on child's ability level)
- Craft – create your own surf board using stickers, markers, crayons
  - Coloring pages
- Building station
  - Legos, plastic stacking blocks, magnetic tiles
- Social skills station – games/activities to help improve their social skills
- Colorful square tiles
- Scavenger hunt
- Photo booth – get your picture taken in front of the beach sign!

7:15-7:20 (wash hands in kitchen, walk through snack line)

7:20-7:35 (prayer, eat snack and child's prepared meal at table)

7:35-8:00 (free to float around stations, maintain 6 ft. distance)

8:00-8:30 (watch movie seated at table)

8:30-8:45 (prepare for dismissal - hand sanitizer for children, coats, volunteers and children each complete exit form)

8:45-9:00 (volunteer and caregiver sign-out)

Figure 2. Schedule of the second respite night.

Appendix N
Formative Assessments

Volunteer Post-Training and Respite Night Feedback

Volunteer Name: _____ Respite Night: _____

1. Do you feel like you need any additional training or education to be successful (feel safe, comfortable, etc.) in volunteering at future respite nights?

☐ Yes ☐ No

If yes, please describe any additional training or education you believe you need in order to be successful.

_____

_____

_____

2. Please provide any additional feedback you believe would make the respite nights more successfu in the future (Note: feedback can be related to the respite night or the training session).

_____

_____

_____

3. Using a 5-point rating scale, please rate your level of comfort related to the following situations. (1-not comfortable, 3-somewhat comfortable, 5-very comfortable)

- Changing a diaper/assisting with toileting 1 2 3 4 5
- Slobber/drooling 1 2 3 4 5
- Redirecting a child who is refusing 1 2 3 4 5
- Assisting a child with feeding 1 2 3 4 5
- Addressing challenging behaviors (biting, hitting, yelling) 1 2 3 4 5
- Overall comfort level interacting with a child with a disability 1 2 3 4 5

4. Noblesville First UMC plans to continue offering quarterly respite nights beginning in August. Would you be interested in volunteering again?

☐ Yes ☐ No

5. How did you hear about the respite nights at Noblesville First UMC?

_____

_____

Figure 1. Formative post-assessment for volunteers.

Appendix N
Formative Assessments

Participant Post Respite Night Feedback

Participant Name: _____ Respite Night: _____

1. Did you have fun tonight? ☐ Yes ☐ No

2. What did you enjoy about the activities? (Child may need prompting)

_____

_____

_____

3. Using a 5-point rating scale, please rate how much you enjoyed the activities.
(1-did not enjoy, 3-somewhat enjoyed, 5-really enjoyed)

• Dancing to music	1	2	3	4	5
• Playing with instruments	1	2	3	4	5
• Eating dinner and snacks	1	2	3	4	5
• Making the craft	1	2	3	4	5
• Watching the movie	1	2	3	4	5
• Playing with balls, building blocks, tossing bean bags	1	2	3	4	5
• Quiet room – sensory bins, swing, bean bags	1	2	3	4	5
• Yoga station – animal walks	1	2	3	4	5
• Bingo	1	2	3	4	5
• Social skills games/activities	1	2	3	4	5
• Overall, how much you enjoyed the entire night	1	2	3	4	5

4. Would you change anything about tonight to make it more enjoyable in the future? (Add certain activity, don't have certain activity, etc.)

_____

_____

_____

5. If we were to have another night like this, would you come back?

☐ Yes ☐ No

Figure 2. Formative post-assessment for children.

Appendix N

Formative Assessments

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Q1.
In the box below, please type your name and the respite night(s) (3/6 and/or 4/3) you have registered your child for.

Caregiver Burden Scale

Caregiver's name: _____ Date: _____

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0 0	1 1	2 2	3 3	4 4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total score: _____

SCORING KEY:
0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

FIGURE 4. Caregiver Burden Scale. This self-administered 22-item questionnaire assesses the "experience of burden."

Adapted with permission from Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980;20:649-55.

Figure 3. Formative pre- and post-assessment for caregivers. Zarit et al.'s (1980) Caregiver Burden Scale converted into online format using Qualtrics. (https://uindy.co1.qualtrics.com/jfe/form/SV_9ZT3QjLU0SQRfAW)

Appendix O

Caregiver "Welcome" Email

Hello, (CAREGIVER)!

Thank you for registering for the respite nights on 3/6 and 4/3 at Noblesville First United Methodist Church. I am Hanna Rose, the coordinator for the Respite Program and the Family Ministry Intern. I am developing this program as part of my final project in my Doctorate of Occupational Therapy studies at the University of Indianapolis.

I am extremely excited to have you and (CHILD) participate in this program! I believe you will both benefit from this program, which is my ultimate goal. In just a few days, I will be sending out a video to you, describing in detail the events that will take place during respite night and providing additional information related to how you can benefit from respite services. NFUMC and I want to serve you and your family to the best of our abilities.

In order to meet university requirements, I have to collect data throughout the development of this program. Below you will find a link to a research-based survey that is used to assess perceived burden among people caring for others with disabilities. There are 22 questions, which will take approximately 5-10 minutes to complete. If you don't mind taking the time to complete this survey, it would greatly benefit the development of this program.

After the completion of the first respite night on 3/6, I will be sending you an additional email with this same survey, and ask you to complete the survey again. The information I gather from these surveys will be very helpful in identifying any changes in your stress levels and psychological well-being as a caregiver.

I know that you have registered (CHILD) for the second respite night on 4/3. This same process will occur for that respite night as well, where I will send out an email with the survey link once again following the respite night.

Thank you very much for registering for these events!! Please do not hesitate to contact me with any questions you may have, or if you would like any additional information. I look forward to talking with you again soon and meeting you! Have a great day!

Here is the survey link where you can access the survey:

https://uindy.co1.qualtrics.com/jfe/form/SV_9ZT3QjLU0SQRfAW

Appendix P
Summative Assessment

Q24. **Do you believe you would benefit from continued respite nights?**

- ○ Yes
- ○ No

Q25. **Noblesville First UMC is planning to take the summer months off from respite nights. We plan to resume quarterly respite nights beginning in August 2021. Our goal is to one day provide monthly respite nights on a consistent basis. Would you be interested in participating in this respite program beginning in August?**

Q26. **If Noblesville First UMC chose to continue offering respite nights, as well as formed an additional group for caregivers of individuals with special needs, offering educational sessions on how to develop healthy respite habits and routines, would you be interested?**

- ○ Yes
- ○ No

Q27. **How did you hear about respite nights at Noblesville First UMC (flyer, email, social media, word of mouth, etc.)? Please describe.**

Q28. **Please provide any additional information related to your experience with caring for a child with a disability that would be beneficial to the continued development of these respite nights.**

Appendix P. Summative assessment for caregivers.
(https://uindy.co1.qualtrics.com/jfe/form/SV_cvV0p3wtRUjyasS)

Appendix Q

Excel® Spreadsheet of Advanced Skills

Ministries Within Noblesville First United Methodist Church		
Family Ministries	**Family Ministries Continued**	**Care Team**
-Communication: providing weekly updates during Staff meetings	-Community Outreach: gave announcements during Family Worship services to promote the respite program	-Community Outreach: volunteered at 1st Wednesday Take-Out Luncheon on 3/3
-Community Outreach: participating in games during Sunday morning worship services that were recorded at the church	-Community Outreach: talked with a woman for an hour on the phone who was interested in learning more about the church, the role of pediatric OT, and provided information on the respite programs	-Communication: connecting with GriefShare coordinator regarding connection to parents of individuals with disabilities
-Organization: gathering supplies/helping with set-up in preparation for Sunday morning Family Worship service	-Leadership: recorded scripture and emailed to Media Specialist; will be played at upcoming church services	-Communication: listening to Daily Prayer Program and providing Hospitality/Parish Care Coordinator with feedback in order to improve program
-Community Outreach: recorded promotional content to be posted on the church's social media platforms for upcoming events related to various Sunday Family Worship services	-Community Outreach: recorded content for two separate Stewardship Moment videos that were played during two separate Sunday church services, promoted respite program	-Communication: collaborated with Hospitality/Parish Care Coordinator regarding list of nursing homes in Hamilton County to possibly contact for future volunteers at respite night
-Management: completed MFMD; completed job description, list of duties and responsibilities, discussed what I wanted respite care program to look like in 2-3 years, connected respite care program to the church's mission and vision, established measurable goals for next 3 months, wrote plan for next 3 months	-Leaderhip: lead Exit 11 (Sunday School curriculum) on Sunday mornings for one hour to 3-4 children	
-Leadership: acted as online host during Family Worship services to increase engagement wtih online viewers	-Organization: organized and cleaned supplies and materials in Educational Resources room	
-Office Management: scanning papers using copy machine, converting "hard copies" into electronic format	-Leadership: attended NFUMC Children's Ministry Volunteer Meeting to take notes for site mentor as she discussed the church's plans for renovation and reopening, promoted respite program	
-Leadership: lead singing motions during Family Worship Service on 1.24 when lead singer/dancer was sick	-Community Outreach: volunteered with the Egged event during Easter	

Ministries Within Noblesville First United Methodist Church		
Sunshine Friends	**Teter Farm**	**Preschool**
-Communication: collaborated with leader regarding March's Sunshine Friends meeting, thinking an Easter theme but unsure of main event for that evening	-Communication: discussed volunteer opportunities regarding opening of greenhouse	-Communication: discussed volunteer opportunities regarding me creating a list of fine-motor activities she can incorporate into her classrooms, possibly creating a Pinterest board of fine-motor activities
-Community Outreach: collaborated with Anita regarding her promoting respite program to Sunshine Friends volunteers and participants	-Communication: visited Teter Farm on 2/3, Operations Manager at Teter Farm explained their mission and vision, how the farm operates, manages its finances, recruits volunteers, and the many projects they currently have planned for the upcoming year	-Technological Experience: created Pinterest board consisting of a variety of fine-motor activities that the Preschool Director can incorporate into her classrooms at the church
-Communicaton: collaborated with leader of special needs ministry to organize March's Sunshine Friends' March Zoom session	-Community Outreach: visited Teter Farm on 2/3, cut lettuce stems for the chickens, removed plastic wrapping from tomato plants in greenhouse	-Organization: collaborated with Preschool Director regarding gathering of necessary supplies and materials for both respite nights
-Leadership: lead virtual Easter egg hunt via Zoom on 3/8		

Appendix Q. Excel® spreadsheet of the advanced skills I obtained through collaboration with various church ministries at NFUMC.