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RESPITE CARE FOR Families *of* Children *with* DISABILITIES

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A UNIVERSITY / FAITH COMMUNITY MODEL

ABSTRACT: *Families of children with disabilities or special healthcare needs report* respite care *as a great need, yet availability of such care is scarce. A partnership developed between a nursing school in the Southeast and a faith community, to provide respite care and summer camps, resulted in a win-win situation for families, children, interprofessional students and educators, the faith community, and volunteers. This article explains the need for respite, how schools of nursing and faith communities can partner, and the benefits to all stakeholders.*

KEY WORDS: *caregivers, children with special needs, disabilities, faith community nursing, interprofessional collaboration, nursing students, respite care, service-learning*

Families of children with disabilities or special healthcare needs experience higher levels of emotional distress, spiritual distress, and social isolation, when compared to families with healthy children (Caples & Sweeney, 2010). Parents of children with physical and/or intellectual disabilities and special healthcare needs rank respite care and summer programs as two of their greatest needs, yet the availability of these programs is scarce (Shelton & Witt, 2011). In response to this need and the lack of programs, a nursing school in the Southeast partnered with a faith community to provide summer camps and respite care events for children with special needs.

The respite program is a win-win for all involved. The program provides a needed community service aimed to reduce parental stress and improve quality of life for the families, a robust interprofessional service-learning opportunity, and a way for faith communities to reach out and serve. Faith community nurses (FCNs) are in an excellent position to develop partnerships between faith communities and universities. Nursing and other health professions students can engage in a service-learning clinical experience that might not otherwise be available.

The purpose of this article is to explain the need for respite programs, how faith communities and schools of nursing can partner to meet the need, and the win-win benefits available to all stakeholders. The low cost and numerous benefits associated with this model for respite care make it a feasible option for families, faith communities, and schools of nursing.

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SPECIAL NEEDS CHILDREN

Approximately one in six children in the U.S. lives with a developmental disability or delay (Centers for Disease Control and Prevention, 2015). According to the 2009–2010 National Survey of Children with Special Health Care Needs, 15.1% of children ages 0 to 17 have special health needs. The incidence in the state of Alabama is higher, with 17.8% of children exhibiting special healthcare needs (Child and Adolescent Health Measurement Initiative [CAHMI], 2012).

Parents…rank respite care and summer programs as two of the greatest desires, yet the availability of these types of programs is scarce.

Families of children with disabilities in Alabama report their top unmet needs are: care during school breaks; respite care; and family support. The most difficult task relayed is finding respite care services during the school year and summer (University of Alabama at Birmingham, 2015). Whiting (2014) conducted interviews with parents of children with special needs, and this need was confirmed. Parents also reported needing an opportunity for social experiences with other families, findings echoed by Caples and Sweeney (2010). Parents voiced feelings of isolation as well as lacking opportunities for social activities. This isolation, affects quality of life for the entire family.

The home environment of a child with special healthcare needs is seldom resonant of a home with healthy children. Many families find great joy in providing in-home care for loved ones; however, the physical, emotional, financial, and spiritual consequences for the primary caregiver and extended family can be significant without additional, outside support (Cunningham, Mulvihill, & Speck, 2009). Respite care, defined as "providing or being temporary care in relief of a primary caregiver" (Merriam-Webster Online, n.d.), can provide the support needed to sustain a healthy family dynamic.

WHAT IS RESPITE?

Respite care is crucial for family health, yet difficult to find (Shelton &Witt, 2011). The goal of respite care for the family of a child with special needs is to provide support in order to maintain the primary caregiving relationship. Respite care that is developmentally appropriate for the child provides a positive experience outside usual family and school activities, while allowing time for the caregiver to attend to needs outside of the special needs environment. Respite care improves the health and well-being of the primary caregiver and family, delays or avoids institutional placement of the child, and reduces the incidence of neglect or abuse. Consistent, reliable respite reduces the incidence of marital strife, separation, and divorce (ARCH National Respite Network, 2015).

Respite care models are based on the location of the care being delivered. ARCH National Respite Network (2015) describes three *in-home* models

and nine *out-of-home* models for respite care—including camps. Each model meets various needs among the special needs community. The program described here focuses on meeting the needs of children and families outside the home, and fulfills the principles of quality respite care (Table 1) (National Respite Coalition, n.d.). This camp model allows children to experience new surroundings, develop peer relationships with healthy children, and receive cognitive, emotional, and spiritual stimulation. Relieved of caregiving, families may enjoy time for projects, rest, or relaxation. Family members receive the benefit of increased time with, and attention from, the person who is usually involved in caregiving (Strunk, 2010).

CAREGIVER SPIRITUAL DISTRESS

Caregivers respond in varying ways to a child with a disability. Some see the presence of the child as a blessing or gift from God. Others may view the presence of the child as a punishment for past sins or failures. Regardless of the perspective, all caregivers are at risk for spiritual distress, due to the disruption of the expected family processes that occur with the birth or adoption of a child with special care needs (Gona, Mung'ala-Odera, Newton, & Hartley, 2011). Spiritual distress is the "disruption in the principle that pervades a person's entire being and that integrates and transcends one's biological and psychosocial nature" (North American Nursing Diagnosis Association, 2015). This distress manifests in various ways, including anger toward God, questioning the purpose of one's existence, confusion about one's relationship with God, and diminishing faith in positive outcomes for the future (Cunningham et al., 2009). Caregivers may seek solace within the spiritual community. Accommodations are present in the public school system, but caregivers often find that the church is ill-equipped to accommodate and assist with special needs. The faith community may see itself as a center for worship and fellowship, lacking an understanding of the unique needs of the family of a child with a disability. As a result, the lack of connection with a faith community can increase distress and promote feelings of hopelessness among caregivers and families (Cunningham et al.).

Table 1: Principles of Quality Respite Care

1. Respite is available.
2. Respite is easily accessible.
3. Respite is affordable.
4. Planned and emergency respite is available.
5. Families have an array of options and can choose services that meet their unique needs.
6. Respite systems address capacity issues and ensure enough providers are available.
7. Respite systems ensure caregivers are aware of and know how to access respite.
8. Respite systems empower caregivers to select, hire, and train competent providers.
9. Respite systems should include families, stakeholders, agencies, and community-based partners.
10. Respite is high quality; evaluation and feedback from families drives program improvements.

Source: National Respite Coalition. (n.d.). Used with permission.

MEETING THE NEED

In response to the increasing community need for respite care, a school of nursing in the Southeast developed a respite care day camp program for children with special healthcare needs (CSHCN). The purpose of the program is to meet the need for skilled respite care for the families of CSHCN, while providing stimulating, Christ-centered activities for the children.

The respite care program was housed at the university for several years and staffed by faculty members and students who had a special interest in the children. As the program's popularity grew, the need to serve more children and families emerged. The need for a child-friendly physical space, along with the need for family spiritual support by a faith community, resulted in a partnership between the university and a local church. The program moved off campus to the church facility.

The church provides child-friendly, handicap-accessible facilities for summer day camps and school year respite care events planned and sponsored by the school of nursing. Each event is staffed by the university, whereas space is provided by the church. Students and educators from the university collaborate in a service and active learning experience to provide appropriate care and activities. The program was initiated by nurse educators, but other disciplines, including physical therapy, education, family studies, communication sciences and disorders, and nutrition and dietetics joined the program, giving educators and students the opportunity to practice interprofessional care in a real-world environment.

Events include short-term respite sessions for children ages 4 to 14, lasting up to 4 hours on Saturdays during the school year, and day camps lasting up to 6 hours daily during the summer. Siblings of the CSHCN also are invited to attend. A typical Saturday respite session may include a holiday party, a parents' night out, or a celebration surrounding a local sports activity. During a typical summer day camp session, children may attend from 2 to 6 hours daily during a 5-day themed camp.

The first camp of the summer is a Vacation Bible School theme, where the CSHCN participate alongside healthy children. Parents also are invited to attend. Day camps are repeated throughout the summer with different themes for the week. Use of the church facilities has allowed the day camp program to expand from the week-long campus-based summer day camp to a program that provides year-round respite, as well as spiritual and social opportunities.

Without the physical space provided by the church, the options for respite activities on campus would be limited to when university classes were not in

session. This partnership allows the program to offer events that deepen family connections to a Christ-centered community. The outreach of the faith community meets children and families where their needs are greatest, allowing them to experience God's love in a real and tangible manner.

Although the church provides an FCN, some volunteers, and physical space, the university provides health-care students and personnel to staff the day camps. Children are assigned to a student nurse for 1:1 care. Other participating disciplines are assigned based on a child's needs. Students are supervised by both registered nurse and nurse practitioner licensed faculty members, along with educators from other disciplines. No child is ever left unsupervised, and the minimum child-to-volunteer ratio is 1:3.

A minimum of three licensed *floaters* are present to assist with needed skilled care. Skilled care is limited to care that parents would perform at home, but are activities above and beyond the expectations of typical childcare. The most common skilled care includes tube feeding, home medication administration, blood sugar monitoring, and nebulizer treatments.

Each child has an emergency action plan, created between the parent and the licensed camp coordinator, based on the child's current home medical management. The child's individualized education plan (IEP) also is requested. In addition to the volunteer educators and students, the university employs staff who are present consistently throughout the respite care events. A camp nurse, who acts as a consultant for the university, is present during respite care programs. An FCN is involved in the program and serves as a liaison between the faith community and the families of the campers.

A formal contract for the camp was drafted between the church and the university. The camp is an approved clinical site for students, and all legal requirements for clinical affiliation have been met. The university assumes liability for the educators, students, and campers during the respite care activities.

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BENEFIT FOR PARENTS: DECREASED STRESS

One goal of the program is providing stress relief and respite to caregivers and families of CSHCN. To assess the effectiveness of the program, pre- and post-intervention surveys measuring parental stress were distributed before and after a week-long camp. The Parental Stress Scale (PSS), an 18-item, 5-point Likert scale, was used to evaluate caregiver stress (Berry & Jones, 1995). PSS scores range from 18 to 90, with a higher score correlating to higher levels of perceived parental stress. Following Institutional Review Board approval, parents of children attending the camp were invited to take the survey (no other caregivers completed the survey). Fifteen surveys were collected prior to the camp. Of this sample, 78.6% were female; mean age was 37.9 years. Following the camp, 12 surveys were completed. Of this group, 91.7% were female; mean age was 38.4 years. Six of the surveys were linked to the same participant pre-intervention and post-intervention. The stress scores of parents decreased from 46.07 (SD = 13.25) pre- to 40.5 (SD = 8.19) post-intervention, supporting the effectiveness of the camp in reducing parental stress. Parents commented that stress was still present, but the camp allowed the family to do things that typically were not possible. Parents commented that they were able to catch up on tasks that had gone undone, appreciating that they did not have to worry about the well-being of the child while in the care of the camp staff and volunteers.

BENEFITS FOR CHILDREN: SOCIAL, INTELLECTUAL GROWTH

The respite camp provides opportunities for children with special needs to play, interact, and spend time with healthy peers. Robertson et al. (2011) noted that CSHCN enjoy time away from their parents while participating in activities with peers. Respite camp assists parents in giving their children opportunities to remove the feeling of social isolation and to increase stimulation.

Children without special needs are *buddies* for the CSHCN. The buddies are role models for CSHCN, making respite camp an inclusive environment. Many buddies are comfortable in an inclusion camp experience because it mimics the public school environment.

In addition to peer modeling, the IEP that guides learning activities in the school year can be continued in the summer. Therapy activities initiated by physical, occupational, and speech therapy can be continued by the university students. For example, speech therapy faculty members and students offer the children who are nonverbal or who have limited language abilities the opportunity to communicate in adaptive ways or to work on speech progression. Individual goals can be reached because of the continued work at respite camp, as a continuation of the IEP and therapy plans of care.

This continued inclusion and prevention of social isolation can result in benefits for the CSHCN and healthy children. Not only are there academic and intellectual benefits from an inclusive environment, but social improvements are seen. Lamport, Graves, and Ward (2012) discussed how children, with or without disabilities, benefit from being together. The CSHCN grow intellectually and socially. Inclusion activities improve empathy, caring behaviors, and new friendships in children, whereas the CSHCN gain independence, increase participation, and have the opportunity to practice communication and social skills (Carter et al., 2015).

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FAITH COMMUNITY BENEFIT: EXTENSION OF MINISTRY

Although healing the spiritual distress of families with CSHCN is a time-intensive process, the linking of a family to a faith community that recognizes their needs is a beginning. Many families of CSHCN are desperate for a church home where they can attend regular activities. Partnering with healthcare schools at a university that have the expertise to offer respite care is a significant community outreach. FCNs are ideally suited to coordinate partnerships with the university, initiating respite ministry with the school of nursing.

Even without prior experience, any faith community can participate in a ministry involving the families of children with special healthcare needs. Operationally, this may be as simple as having a designated volunteer assigned to a child during church meetings and activities. This volunteer need not have healthcare experience, as the likelihood that a child will have a need during a typical 1-hour church event is small. If the volunteer knows how to locate the caregiver should a need arise, and the caregiver is comfortable knowing the volunteer is attentive, a sense of community and fellowship is developed. By fostering this partnership between the faith community and the family, the church can lessen spiritual distress by allowing the family to participate in activities. Without such services, many families would not be able to attend.

For Christians, ministry of the faith community to the families of CSHCN engages the community in fulfilling the teaching of Jesus: "When you give a banquet, invite the poor, the crippled, the lame, and the blind, and you will be blessed. Although they cannot repay you, you will be repaid at the resurrection of the righteous" (Luke 14:13, NIV).

UNIVERSITY BENEFITS: SERVICE-LEARNING, INTERPROFESSIONAL COLLABORATION

The mission of many universities emphasizes service-learning as a part of a holistic educational experience. Service-learning is defined as "a teaching technique in which students participate in a community service activity that is clearly related to the academic objectives of a course and/or major field of study. As a result, students gain relevant, hands-on experience, while improving the quality of life of citizens" (Northwestern State University of Louisiana, n.d.). Another university defines service-learning as "a teaching and learning strategy that integrates meaningful community service with instruction and reflection to enrich the learning experience, teach civic responsibility, and strengthen communities" (Duke University, n.d.). Serving as a camp volunteer enables students from various disciplines to meet this objective.

The tripart role of the academician includes teaching, scholarship, and service. Educators who facilitate the respite care events engage in service that supports the roles of teacher and scholar. Student learning is enhanced as educators demonstrate the roles of master clinician and master teacher. Educators can be afforded the opportunity for scholarship through obtaining grant support for the program, engaging in research specific to their discipline, and disseminating research through presentations and publications.

As disciplines beyond nursing joined in our program, an opportunity emerged to accentuate and expand best practices in interprofessional education, collaboration, and service. Interprofessional education is recommended for all health professions by the World Health Organization (2010):

> *Interprofessional education occurs when students from two or more professions learn about, from, and with each other to enable effective collaboration and improve health outcomes. Once students understand how to work interprofessionally, they are ready to enter the workplace as a member of the collaborative practice team. This is a key step in moving health systems from fragmentation to a position of strength.*

Children who attend the camps are assigned a nursing student, along with a team of students from disciplines pertinent to the care required. By utilizing a collaborative team approach, students learn the value and strengths that each discipline provides.

While some students primarily desire to serve, others may prefer an

immersion experience, with the opportunity to gain academic credit. Clinical exposure to CSHCN in a prelicensure nursing program may be limited, whereas graduate students may have little-to-no recent clinical experience with children. To meet the need and student desire for exposure to this patient population, the school of nursing developed an elective academic course that includes service in the respite care camp. Students who desire elective academic credit and wish to work with CSHCN may take the course for additional clinical experience. After administering a feeding via a gastrostomy tube, one graduate student remarked, "In all my years as a nurse, this was my first experience with tube feeding a child" (Student #1, personal communication, July 25, 2015). Another student commented that she'd had no other educational experiences that involved children with disabilities (Student #2, personal communication, July 26, 2015). This pedagogical approach, utilizing the respite care program as a clinical experience, benefits both the student and the university. Students receive the benefit of interprofessional service-learning with the option of academic credit, and the university benefits by providing another option for elective course credit, while promoting faculty development.

University partnership with the faith community allows this private Christian university to cultivate a Christian worldview. Due to the unique learning environment of the program, students foster an understanding in the theological perspectives taught in Scripture through the application of biblical doctrines. Service in the respite program allows students the opportunity to practice their respective disciplines but also deepens their understanding of biblical perspectives. "Each of you should use whatever gift you have received to serve others, as faithful stewards of God's grace in its various forms" (1 Peter 4:10, NIV).

An intangible benefit is the kinship that develops through service to a common cause. Students often comment that they appreciate working closely with the faculty and enjoy getting to know those from other disciplines. Team-building benefits are evident as students care for the children and learn from each other. Educators and students describe the experience as enjoyable and unique. Students have commented that the camp was more gratifying than any other clinical experience. Faculty members echo these sentiments, emphasizing that achieving service hours at the respite camp is the most desired service activity of the year.

REPLICATING THE PARTNERSHIP

This university/faith-community partnership model is an effective and cost-efficient way to meet an increasing community need. As the rates of children with developmental disabilities continue to rise, communities must find creative, cost-efficient, appropriate ways to meet these special needs. Families who do not qualify for state services have limited resources for respite care (Swenson & Lakin, 2014). Twenty-one percent of parents of children with special healthcare needs report financial problems (CAHMI, 2012). CSHCN often require specialized care such as nursing, physical therapy, speech therapy, occupational therapy, and nutritional consultation. The cost of providing respite care and camps through a traditional fee-for-service model would be too expensive for typical families. Ten years ago, Whitlatch and Feinberg (2006) reported cost per hour of respite care ranged from $8.48 to $12.67, depending on whether the care was provided by a paid family member/friend or a company. Not only is cost a concern, but unmet respite care needs are greatest in the South; therefore, geographical location plays a role in services a family can obtain (Fulda, Johnson, Hahn, & Lykens, 2013).

The university/faith-community partnership has proven to be an answer for many families. A significant care gap in the community is met by providing a reduced cost respite care, while providing the appropriate care CSHCN require. Because of the partnership, a child can attend a summer day camp, 6 hours a day for 5 days, for $100 weekly ($3.33 an hour). Camp families report they are grateful for the program because the few options that do exist in the community are not affordable.

This low cost is feasible because the majority of care is provided by healthcare educators and students, as well as community and church volunteers. Church facilities, unused the majority of the week, provide physical space. The in-kind donation of the church facilities eliminates the need for purchasing or leasing physical space. The program also elicits support from additional community partners who help provide food and activities for children and staff. For example, a local, not-for-profit food kitchen has provided lunch at the full-week summer camps for the last three summers. Other organizations have visited with therapy animals, friendship, and entertainment options. Church members, youth groups, and local high school students also volunteer.

Web Resources

- ARCH National Respite Network and Resource Center—http://archrespite.org
- Family Caregiver Alliance—https://www.caregiver.org/family-care-navigator

CONCLUSION

The need for respite care, social interaction, and spiritual encouragement in families of CSHCN is pervasive and ongoing. Meeting these needs can be time- and resource-consuming for those who attempt to provide care. Families need time for relaxation and renewal. Children need on-going stimulation and therapy. Families and children both need the spiritual attentiveness inherent in a faith community. The partnership of a faith community and a university is an effectual collaboration that can reach these needs. Christ-followers are called

to care for these children and families: "As you did it to one of the least of these my brothers, you did it to me" (Matthew 25:40, ESV).

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