

Camp New Hope

Mia Falbo, Riley Black, Hannah Considine, Ashley Matusiak, Cheyenne Gardner, Airelle

Mitchell

Lakeview College of Nursing

Populations and Global Health

**An inside look on Camp New Hope** (Introduction: Mia Falbo)

The view of special needs is seen in many different ways. Each individual may have a cognitive, physical, or sensory impairment. The special needs population requires aid from different areas, including physical, speech, and occupational therapy. As a nurse, it is vital to advocate for the needs of these individuals. Having a child with special needs can be very time consuming and challenging for a parent. Camp New Hope gives individuals with special needs an outlet to experience life in a new and exciting way. It is located on Lake Mattoon, where the campers are cared for by being aided in daily activities. The campers are involved in my exciting activities, like going for train rides on the grounds, boat rides on the lake, and many arts and crafts. This camp allows these individuals to expand their social intellect and interact with other individuals who experience different daily life challenges. Physical activity is not only good for the body and decreases specific risks but also for the mind—various activities for these campers to aid in the wellness of these individuals. As a group, over the weekend, we were able to volunteer at Camp New Hope and aid in the experience of these individuals. We decided to choose this location due to the enormous care and compassion not only the workers have but seeing the smiling faces of these people as they participate in the following activities. As a nurse, gaining more experience in the community will help increase satisfaction in working in different settings. The population of special needs individuals is growing and the need for care is expanding more increasingly in demand each day.

**Riley Black**

Respite care is a service with many benefits, but it is not always easy for parents or caregivers to gain access. Caring for a child with special care needs may require near-constant attention. This care is time-consuming and limiting for parents or caregivers. Respite care provides caregivers time to rest and unwind while their child is cared for outside the home. Respite care benefits the children as much as the caregivers, allowing time for social interaction with respite staff and other children (Breneol et al., 2019). Respite care is not only a scheduled need. There are times when families and caregivers will experience emergencies and require respite care, which can be challenging to access in a timely manner (Breneol et al., 2019). Complications in receiving respite care are not limited to emergent situations. There are obstacles for caregivers looking for first-time care or transfer of care. Many respite care services have lengthy waiting lists, delaying access to respite services for many caregivers (Breneol, 2019). One final complication is that while caregivers may be away from the child or children they care for, they may still experience high-stress levels. Until the parent builds a trusting relationship and gains confidence with the respite service, they will likely spend more time worrying about the care and comfort of their child rather than regrouping and relaxing (Breneol, 2019). While respite care offers many benefits to caregivers and children, it is clear that there are still challenges associated with receiving respite care for these families.

Caring for children with special care needs comes with many challenges that can majorly affect families and caregivers in several ways. Whitmore and Snethen collected data from parents of children with special care needs and shared their findings. Themes they noted from the caregivers are trying to meet the complex needs on their own, the stress of constantly dealing with multiple stressors simultaneously, and the lack of time to meet their own needs or the needs

of the family (Whitmore & Snethen, 2018). These challenges are precisely why respite care is offered to these caregivers. Whitmore and Snethen also documented praises for respite care from families and caregivers. Some significant benefits caregivers expressed are how it helped save their jobs, allowed them to catch up on sleep, and helped restrengthen the bonds of their marriage and family (Whitmore & Snethen, 2018). The praises continued with more psychological benefits. Respite care provides caregivers with hope and allows them to get a break from the constant responsibilities of their daily routine (Whitmore & Snethen, 2018). It is easy to say that respite care certainly is a necessary service available to these caregivers to help maintain their sanity and meet the needs of their families and their well-being.

### **Ashley Matusiak**

Therapeutic recreation camps such as Camp New Hope can positively impact social support through peer bonding. A research study conducted by the University of Texas Southwestern Medical Center states there is "evidence suggesting short-term psychosocial benefits of camps for children with chronic diseases," which include "improvements in social interactions, acceptance, self-perception, and autonomy" (Saez et al., 2022). Although this study only measured the benefits of camps for children with chronic illnesses, such as diabetes or cancer, those with intellectual or developmental disabilities may also benefit from therapeutic camps. Those with intellectual or developmental disabilities are also more likely to have chronic disorders, making therapeutic recreation camps an excellent intervention to provide social connectedness through shared experiences among participants. At Camp New Hope, participants played games in a judgment-free environment with peers who understood each other's

difficulties. Furthermore, therapeutic recreation camps also provide an outlet for physical activity.

Obesity has become a growing epidemic and includes all demographics, although this is a more significant issue among those with intellectual and developmental disabilities. Catherine Sanner, a Ph.D. student from the Department of Psychology in California, states that "individuals with intellectual and developmental disabilities are particularly vulnerable to obesity due to additional factors" (Sanner et al., 2021). These additional factors are "physical limitations, medications with effects on appetite, sensory problems affecting nutritional choices, and increased behavior problems placated with food" (Sanner et al., 2021). Recreational camps such as those run by Camp New Hope provide many physical activities for camp participants, including bounce houses, swimming, and even a 5K run. For those with physical limitations, all activities for every level are available to get participants active and socializing, including cornhole, the cake run, and the bubble station. Sanner also writes, "social communication deficits with intellectual disabilities and developmental disabilities pose as additional barriers to physical activity and likely have a negative impact on involvement in sports and other physical activities" (Sanner et al., 2021). At a therapeutic camp such as Camp New Hope, those with intellectual and developmental disabilities can feel comfortable trying new games with peers and come home with a positive active experience that can increase their confidence.

### **Hannah Considine**

**Who are the beneficiaries and what are the reasons for non-utilization of care respite and support services? A cross-sectional study on family caregivers**

Caregivers of those with developmental and physical disabilities assume substantial caregiving responsibilities for persons with chronic conditions, which negatively impacts their lives. Respite care and other similar services provide temporary relief and support for caregivers (Huang et al., 2021). It is essential to not only offer these types of services for caregivers but to explore the reasons for the non-use of these services. Utilization of respite care is generally low in several countries despite high levels of need. There are several reasons caregivers may not seek respite care, such as the caregiver's cultural understanding of the healthcare system, income, education level, and geographic location (Huang et al., 2021). Providing low-cost, easily accessible respite services for this population would significantly impact the well-being of caregivers and individuals with a disability. Respite programs should be adapted to their intended users' cultural, regional, and personal contexts. This goal is best achieved in coordination with local healthcare professionals who can identify needs, provide individual information, initiate referrals, and integrate care activities into a more extensive support plan (Huang et al., 2021).

### **A Systematic Review of Therapeutic Recreation Camp Impact on Families of Children With Chronic Health Conditions**

Children with chronic illnesses often experience adverse effects on their health-related quality of life, behavior, and psychosocial functioning; however parents and siblings of these children are also negatively impacted (Rea et al., 2019). Parents are burdened by balancing work, household routines, medical care for their ill child, and ongoing care for their other child. They may experience increased marital strain and a more significant financial burden. Siblings may also take on more adult-like responsibilities and cope with their fears and feelings regarding the illness. The long-term nature of a chronic illness or health condition is a source of ongoing stress for the entire family (Rea et al., 2019). Therapeutic recreation camps for children with chronic

illnesses and their families are an increasingly popular method of psychosocial intervention. Children with chronic medical conditions often report positive psychosocial change after attending camp, including increased hope and a positive outlook regarding their future (Rea et al., 2019). Since children with chronic illnesses have unique needs and challenges, the camp can serve as a setting removed from the hospital or medical clinic in order to provide this type of care. This setting appears to be beneficial in providing respite, social support, and improvements in psychological health for parents and siblings. Therapeutic recreation camps should be utilized as often as possible because evidence concludes it positively impacts the whole family.

### ***Cheyenne Gardner***

Staff and family views of alternative respite services for adults with intellectual disabilities – aims, outcomes and experiences. Traditional residential respite care is historically the most common form of respite care. This care provides in-home relief for caregivers and family members to receive a break from caring for an individual with disabilities. In recent years there has been a transition from traditional residential respite care to alternate forms of respite care. Alternate forms of respite care emphasize providing new opportunities and integration into the community for the patients while providing a break for the caregivers. The goal of this study was to gather the thoughts and opinions of both the caregivers of the family and the staff providing respite relief regarding traditional respite care versus alternative respite care. Family members and caregivers discussed their thoughts on alternative respite care. Through these interviews, the interviewees said that these alternative respite care methods could benefit both parties. One family member said that their son was gaining confidence, making new friends, and improving skills with the alternate respite care (Guerin et al., 2019). Alternative respite care gives individuals with disabilities a new environment and opportunities they would not have if

they received care exclusively in the home. The family member said he looked forward to it a week in advance and reminded her that he would be gone that day (Guerin et al., 2019). The family members discussed many other positive outcomes. The interviews found that alternative respite care can provide many more opportunities and positives for the parties involved. However, it is essential to note that all individuals will have different needs and abilities, so the type of care will need adjusting for each individual.

### **Perspectives Worth Sharing- Respite Care Camps: Helping Parents and Children with Special Healthcare Needs.**

Respite care camps aim to provide individuals with disabilities opportunities to grow personal and social skills, learn and have fun while providing their caregivers time to themselves to focus on their health and well-being. Studies have shown that parents and caregivers had decreased stress after sending their children to respite care camps. One parent said, "I am still stressed, but it allowed me to do things that life with my child does not allow me to do" (Johnston, 2017). The campers enjoy various activities, including singing, crafts, and playing outdoors, while receiving the appropriate care they need. These camps also provide training for students entering the healthcare field. The students who work as faculty build relationships with the campers while growing their skills for their future careers. CampUs, discussed in this article, has partnered with the local college and church to receive appropriate staff and funding. A professor started this camp after struggling to find a summer camp that could accommodate her daughter's needs (Johnston, 2017). Respite camps like this one have a positive impact on all the individuals involved, and it is essential that these camps exist and can continue to offer the camp experience to all individuals regardless of their health needs.

**Arielle Mitchell****A Narrative Review of Pediatric Respite Care Initiatives in the United States**

Families caring for a child with special needs can struggle with continuously providing extensive medical care can be straining and mentally overwhelming. Many caregivers who seek resources for respite care services have difficulty finding a respite facility (Ferragamo et al., 2022). Not having these resources can cause issues for the caregiver's well-being because they do not have much time for themselves. Providing these resources and programs to have respite care included in palliative care could vary state by state. Illinois has implemented a state plan to include palliative care services at home and at a facility that includes respite care and Medicaid benefits (Ferragamo et al., 2022). Having these resources available can provide caretakers with time to provide self-care and reduce mental health issues in the long run. Different types of respite care can be given through home, facility, community, and overnight care (Ferragamo et al., 2022). Providing these resources to families with special needs can provide breaks with trusted individuals and should be provided to all families in need. Like Illinois and other states, implementing these changes in respite care and providing these resources can change many caretakers' lives and families' mental health.

**Effectiveness of Respite Care via Short-Stay Services to Support Sleep in Family****Caregivers**

Many caregivers struggle with caring for a family member with a disability because it can be time-consuming and tiring for the individual. While caring for a special needs child, they need a full-time advocate and caretaker. This article, using quantitative data, explains how families can suffer from sleep disturbances due to the care and needs of each client through a quantitative

research approach (Sakurai & Kohno, 2020). Further, respite care is provided to help families relieve their duties by bringing their special needs child or adult to a safe place. Since sleep disturbances have been an ongoing problem, there can be risk factors that come with it. Sleep disturbances can lead to obesity, diabetes, stress, and cardiovascular diseases (Sakurai & Kohno, 2020). Families who take continuous care of their family members must take short breaks for their well-being because this can be strenuous for the caretaker. Having camps and places with organizations with short stays for families in need can allow caregivers to take time to increase their sleep and decrease their sleep disturbances while the client is at a service like these short-stay services. The case study concluded that cardiac function was decreased, and sleep was more efficient when the client was in a short-stay respite care service (Sakurai & Kohno, 2020). All in all, respite care services with short stays services will help caregivers have time off and can help with mental health and overall sleep functions.

### *Mia Falbo: Conclusion*

The population of special needs individuals is growing, and the need for care is increasing demand each day. People with special needs face different obstacles every day. Camp New Hope gives these individuals an opportunity to expand their minds and participate in activities that advocate for the well-being of these different individuals. The opportunities presented at this facility give these campers a unique chance to be cared for in a different setting. The campers' families have a chance to debrief while their child is being taken care of at this establishment. Camp New Hope truly gives these outstanding individuals, and their families new hope of what life can be like with a disability.

## References

- Breneol, S., King, S. T., Best, S., McKibbin, S., & Curran, J. A. (2019). Respite care for children and youth with complex care needs and their families: A scoping review protocol. *JBIS Database of Systematic Reviews and Implementation Reports*, 17(7), 1297-1304. <https://doi.org/10.11124/JBISRIR-2017-003998>
- Ferragamo, T., Pituch, K., Sorkin, T., et al. (2022). A Narrative Review of Pediatric Respite Care Initiatives in the United States. *Journal of Hospice & Palliative Nursing*, 24, E172-E182. <https://doi.org/10.1097/NJH.0000000000000867>
- Guerin, S., Nicholson, E., Keogh, F., et al. (2019). Staff and family views of alternative respite services for adults with intellectual disabilities – aims, outcomes and experiences. *International Journal of Developmental Disabilities*. <https://doi.org/10.1080/20473869.2019.1665773>
- Huang, J., Münzel, N., Scheel-Sailer, A., & Gemperli, A. (2021). Who are the beneficiaries and what are the reasons for non-utilization of care respite and support services? A cross-sectional study on family caregivers. *BMC Health Services Research*, 21(1). <https://doi.org/10.1186/s12913-021-06651-6>
- Johnston, K., Cunningham, J., & Buckner, E. (2017). Respite care camps: Helping parents and children with special healthcare needs. *Compass Point*. <https://web.p.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=7&sid=8e08fa11-0d49-4f1f-a5da-c63448976624%40redis>
- Rea, K. E., Quast, L. F., Stolz, M. G., & Blount, R. L. (2019). A systematic review of Therapeutic Recreation Camp Impact on families of children with chronic health conditions. *Journal of Pediatric Psychology*, 44(5), 542–556. <https://doi.org/10.1093/jpepsy/jsz00>

- Saez, C., Nassi, L., Wright, T., Makris, U. E., Kramer, J., Bermas, B. L., Solow, E. B., & Bitencourt, N. (2022). Therapeutic recreation camps for youth with childhood-onset systemic lupus erythematosus: perceived psychosocial benefits. *Pediatric Rheumatology Online Journal*, 20(1), 39. <https://doi.org/10.1186/s12969-022-00702-w>
- Sakurai, S., and Kohno, Y. (2020). Effectiveness of Respite Care via Short-Stay Services to Support Sleep in Family Caregivers. *International Journal of Environmental Research and Public Health* 17, no. 7: 2428. <https://doi.org/10.3390/ijerph17072428>
- Sanner, C. M., Neece, C. L., Herbozo, S., & Baum, M. F. (2021). A pilot study of enhanced operation fit: The feasibility of a camp-based health intervention for ethnically diverse families of children with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities : JARID*, 34(2), 624–633. <https://doi.org/10.1111/jar.12832>
- Whitmore, K. E., & Snethen, J. (2018). Respite care services for children with special healthcare needs: Parental perceptions. *Journal for Specialists in Pediatric Nursing*, 23(3). <https://doi.org/10.1111/jspn.12217>

