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Seven Respite Services Selected as Innovative and Exemplary in National Search

Washington, D.C., July 13, 2020 — The ARCH National Respite Network and Resource Center is pleased to announce the recognition of seven ***Innovative and Exemplary*** respite services from across the country. In addition, four services were identified as ***Innovative***, and five as ***Rising Stars***. Each respite service met a [stringent set of criteria](#) for selection in each category and all have outstanding programs that address the needs of family caregivers of children, adults or older adult family members. Having met all of the criteria, respite services selected as both Innovative and Exemplary will receive a small honorarium from ARCH in recognition of their achievements.

Respite is the most frequently requested support service among the nation's 53 million family caregivers, yet 86% do not receive respite services, despite the proven benefits to caregivers and care recipients. Respite for these families can help reduce caregiver stress, improve caregiver and family health and well-being, help avoid more costly out-of-home placements, and may even help to reduce the likelihood of abuse or neglect.

The pandemic has intensified social isolation among family caregivers and their loved ones, further jeopardizing their well-being. Respite may be their only link to services and supports. During the pandemic, some of the respite services recognized by ARCH may have had to implement strict health and safety protocols, to curtail services, or offer alternative supports, but they continue to provide a critical lifeline to the caregivers they serve.

By recognizing high quality respite services across the country, ARCH hopes to encourage the study, expansion and replication of such services.

For more detailed information about each program and the selection process, see the attached and the ARCH [website](#).

The ARCH National Respite Network and Resource Center, a project of the Chapel Hill Training-Outreach Project, Inc., assists and promotes the development of quality respite and crisis care programs; helps families locate respite and crisis care services in their communities; and serves as a strong voice for respite in all forums. The ARCH National Respite Network includes three initiatives: the National Respite Locator, aiding families to locate respite providers in their community; the National Respite Coalition, advocating for preservation and promotion of respite in policy and programs at national, state, and local levels; and the Lifespan Respite Technical Assistance Center, providing respite training and technical assistance to [Lifespan Respite grantees](#), [State Respite Coalitions](#), ARCH's membership, and the general public.

The initiative to recognize and promote exemplary and innovative respite services was supported in part by the Wareheim Foundation. The ARCH National Respite Network and Resource Center is funded in part by the Administration for Community Living, U.S. Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

Visit archrespite.org or call (703) 256-2084 for more information.

2020 Innovative, Exemplary and Rising Star Respite Services Selected by the ARCH National Respite Network and Resource Center

To read more about the selection criteria, visit the [ARCH website](#).

Innovative and Exemplary Respite Services

Caregiving Youth Project of the American Association of Caregiving Youth *Boca Raton, Florida*

The **Caregiving Youth Project** supports young people who are providing care for a family member. These youth spend an average of twenty (20) hours per week caring for loved ones and often sacrifice their personal well-being in service to others. Respite is part of the array of services offered so the young caregiver will have opportunities to engage in school, have a 'normal' social life and positive, age-appropriate experiences that would otherwise be inaccessible to them. Data collected on caregiving youth who participate in the project demonstrate strong positive outcomes related to school attendance and academic success as well as positive outcomes on other measures of well-being. The respite services were initiated due to the expressed needs of caregiving youth. Learn more about this program by visiting their [website](#).

ChildServe Respite *Johnston, Iowa*

The needs and priorities of caregivers and their children are foremost in the development of respite options offered by **ChildServe**. Caregivers with children birth to 25 years with a wide range of needs, including complex medical, autism, behavioral, and physical disabilities, can receive planned and emergency respite. The respite can be in-home, center-based, community-based, or at summer camp according to the families' requirements. Their person-and family-centered approach is unquestionable. The respite providers, including licensed and degreed medical staff, are carefully screened and trained. Recognizing that some caregivers and their children feel more comfortable in the care of someone they are familiar with, provided they meet strict screening guidelines, ChildServe will hire and train providers identified by the caregivers. ChildServe helps parents access funds to pay for the respite through home and community service waivers, but no one is turned away due to inability to pay. ChildServe collects outcome data and has maintained implementation guidelines that can be used for replication. Learn more about their outcomes, service model, and implementation procedures at their [website](#).

Lifespan of Greater Rochester Caregiver Respite Program *Rochester, New York*

The **Caregiver Respite Program** at **Lifespan of Greater Rochester**, New York, in a strong partnership with the Alzheimer's Foundation, has for six years served persons with Alzheimer's disease and other dementias and their families by supporting and empowering caregivers, care recipients, and volunteer providers. Using a clearly defined match process including conducting caregiver interviews and

assessments, and identifying care recipient and volunteer characteristics and interests, the Caregiver Respite Program supports long and close family-provider relationships. *Powerful Tools for Caregivers* courses are offered as part of a family-centered approach. Volunteer training and support includes Alzheimer's Association sponsored training as well as training in policies and procedures, job roles and responsibilities; and ways to interact socially given symptoms associated with Alzheimer's and dementia. Forums for discussing challenges, brainstorming and peer-to-peer support are scheduled regularly. Formal, external program evaluation, seen by the program as vital to documenting program effectiveness and supporting efforts to maintain funding, was part of the Caregiver Respite Program's design from the outset, and includes a specially designed database. A comprehensive replication manual and an evaluation report are available by contacting the program. Visit their [website](#).

Rhode Island CareBreaks Program
Cranston, Rhode Island

The **Rhode Island CareBreaks Program** has supported caregivers of children and adults with long-term disabilities or medical needs, especially underserved families for whom respite services are unavailable or inadequate, using nursing students as respite providers through their nursing curriculum. Four of Rhode Island's six colleges and universities work in partnership with the Rhode Island Office of Healthy Aging to provide training and support of junior and senior level nursing students. In addition to strengthening the respite workforce and sensitizing pre-service health care professionals to the importance of and need for respite, individual university programs allow students to specialize in policy, leadership and legislative advocacy projects. The CareBreaks program has developed a replication toolkit, *Supporting Family Caregivers*, for use by other institutions of higher learning. An evaluation plan is used to ensure quality assurance in day-to-day services, and to document achievement of goals and objectives. Outcome data demonstrate that CareBreaks services relieve caregiver stress, and qualitative data indicate that the bonds created between parents through a group respite component reduce social isolation. Watch the [video](#).

RISE Wisconsin, Inc., The Respite Center
Madison, Wisconsin

The **Respite Center** was conceptualized over forty years ago, when concerned staff at a local child-care center began looking for ways to support families who had no informal support systems to provide care for their children during times of crisis or high stress. The center began providing crisis care as well as planned respite for vulnerable families at risk for child maltreatment. Later, they joined with other community service programs and created a larger organization, RISE Wisconsin. The Respite Center is a corner stone of RISE. Although they collect fees on a sliding scale for services, no family is ever turned away because of inability to pay. The Respite Center is inclusive and responsive to the varied medical, social emotional, mental health, and developmental needs of children. Learn more from their [website](#).

Ryan House
Phoenix, Arizona

Ryan House in Phoenix, Arizona, has been providing pediatric respite, life-enhancing therapeutic activities, and pediatric palliative and hospice care to help families navigate their children's life limiting and end-of-life conditions. In existence for ten years, Ryan House serves 200 children and families each year through a continuity of care model in partnership with families and multiple medical and therapy providers. Children may stay up to 28 nights each year, with schedules varying according to family needs and preferences. On-line support is available to families 24/7, and volunteers are available to help families meet more global needs, such as grocery shopping. Families are supported in planning their children's visit as well as their own use of respite time. Ryan House regularly collects process and outcome data, as well as cost data, and they intentionally diversify funding sources to support sustainability. Relationships with families are sustainable as well, as is evidenced by their beautiful Memorial Garden. To learn more about Ryan House or to take a virtual tour, visit the [website](#).

TRE-ADD Respite Choices
Community Living Toronto
Toronto, Ontario

TRE-ADD Respite Options of Community Living Toronto offers hourly, overnight, camp, and community-based respite for children and adults with complex medical needs. Respite services are for children with autism whose complex behavioral needs prevent them from participating in other community respite options. The overall goal of Respite Choices is to provide children with services and supports to prepare them to transition to a less intensive community-based respite program. Respite families may book up to one weekend a month and two weeks during the summer for their summer camp respite program. TRE-ADD Respite Choices has a multi-disciplinary team that includes the respite coordinator, behavior services consultant, program manager, supervisor, and support workers. The program collaborates with other community professionals, including school staff, teachers, psychiatrists, general practitioners, pharmacists, speech and language pathologists, and occupational therapists. Respite Choices uses an Applied Behavior Analysis approach in all aspects of programming with an emphasis on communication, life skills and recreational activities. In addition to implementing behavior programming and providing ABA services, support workers assist the individuals with hygiene routines, household tasks, food preparation, and community engagement. Learn more at their [website](#).

Innovative Respite Services

Central Minnesota Elder Network, Respite Care Program

Alexandria, Minnesota

This rural program has been in existence for 15 years with the overriding goal of providing caregiver support while enriching the lives of care receivers. Their program offers three respite services: In-Home Respite, The Gathering, and ongoing Caregiver Coaching. Their in-home respite program provides professionally trained volunteers who provide respite one day a week for up to four hours. The volunteers provide socialization, safety, and security for adults who are unable to be left alone. Additionally, twice a month they provide an out-of-home respite activity program, *The Gathering*, which provides socialization, friendship and fun for care receivers. *The Gathering* is coordinated by an RN and staffed by the Program Coordinator and trained volunteers at a 1:1 to 1:2 staff to client ratio. The third respite program is *Caregiver Coach* which provides reassurance, resources, education and support from admission and beyond discharge to assist in the care giving journey and grieving process. Coaches have gone through a rigorous training program. The Coaching Program is offered to all caregivers who receive the respite services. Learn more from their [website](#).

Nurturing Newborns

Centennial, Colorado

Nurturing Newborns offers respite to families in crisis. They serve caregivers of infants and children using a model based upon the [Fussy Baby Network Model](#). Nurturing Newborns supports parents through an infant mental health and prevention-focused home visiting model and provides respite during times of need. Their program focuses particularly on parents of children who have spent time in a NICU. Upon their child's return home, parents often feel anxious, scared, isolated and overwhelmed. Through their respite program, trained and experienced staff offer short-term support and care for parents and their children during times of difficulty. The goal of the respite program is to help parents come through a hard time with caregiving and feel stronger, more confident, and competent. This population is often underserved, and they require skilled respite providers. The duration of services typically ranges from three to six months, but families who are at increased risk or whose children have disabilities have received services for up to two years. Learn more on the [website](#).

SOAR 365 Respite

Richmond, Virginia

SOAR365 provides an array of services for people birth to adulthood who have disabilities as well as respite for caregivers. Services include pediatric therapy, adult day programs, workforce development, summer camp, and business solutions. They provide out-of-home respite services on the weekends, Friday-Sunday, 46 weekends a year. During these weekends, a robust schedule of activities is offered, such as arts and crafts, swimming, horseback riding, games, recreation and physical fitness, and cooking classes. They also offer trips off site to events and community gatherings. Their respite program serves individuals who may need medical care and assistance with eating, using the restroom and bathing.

Families using SOAR 365 services are involved in the service planning process and their opinions are important to the success and growth of the program. Visit their [website](#).

The ALS Association, MN, ND and SD Chapter, Jack Norton Family Respite Program
Saint Paul, Minnesota

The **ALS Association of Minnesota, North Dakota and South Dakota** pays a partnering home care agency to provide a professional caregiver in the home of families caring for a loved one with ALS. The Jack Norton Family Respite Program was developed by a man when he was in the early stages of ALS. He wanted to make sure that his wife had supports in place as his condition worsened. The program was developed on the understanding that the knowledge and supports required as the disease progressed required ever-increasing help for caregivers. Trained, professional care providers assist the loved one with activities of daily living such as transferring, bathing, eating, and toileting so that family caregiver feels safe to leave the care recipient at home while receiving respite. If the care recipient requires skilled care such as suctioning, trach/vent care, etc., the organization will cover a nurse in the home. The agency connects the caregiver with the respite provider and pays for up to 18 hours of respite per month. Learn more at their [website](#).

Rising Stars

Bethel Life, Loving Hands
Greenville, Pennsylvania

Loving HANDS is a faith-based program with a monthly family-night-off for caregivers of children with special needs as its centerpiece. Relationships across individuals, families, the local faith community, schools, and service organizations in the community have developed and been strengthened through the family night-out. Those relationships have led to increased levels of inclusion in the community. Although there are no expectations that participating families attend the sponsoring church, attendance of special-needs families has increased. Volunteers ensure that accommodations are made during church services so no person will be excluded. Volunteers at Loving Hands come from other churches, schools, community organizations, and community members at large. Intentionally, and in some cases unexpectedly, long-term relationships have been formed between families with individuals with special needs and the Loving Hands volunteers. This has led to a more inclusive community. Loving Hands has been replicated at eight locations in other states. Learn more about this Rising Star Respite Program at their [website](#).

Alzheimer's Disease Caregiver Support Initiative
Plattsburgh, New York

The **Caregiver Support Initiative** provides services for caregivers of individuals with Alzheimer's and other types of dementia. Care Navigators work with caregivers to educate them about the support services they may require in their caregiving journey. Respite services are provided by trained professionals who may be volunteers or paid individuals. The services are person-centered to reflect

both the cultural needs and level of care of the caregiver and person with dementia. Services are consumer-directed to provide caregiver choice of providers. Locations for respite services include, but are not limited to, the care recipient's home, adult day program, or other residential facility. There is no charge for services of the Caregiver Support Initiative. Learn more at their [website](#).

Dutter House
Beloit, Wisconsin

Dutter House is a community-based respite program offered in a warm and welcoming home by skilled and trained volunteers. It was started by a long-time teacher who bought a house and obtained a state license for family day care specifically to provide respite for caregivers of children with conditions such as autism, traumatic brain injuries, or other disabilities. The respite services, which are free to families, are supported through public and private funds. Families can schedule regular 3-hour visits, usually 2-3 times per week and occasionally on weekends. Although most of the families served are local, some families travel from up to 50 miles away to receive respite in this friendly, child-and family-centered respite program. Visit their [Facebook page](#).

Family to Family Adult Care Service
Memphis, Tennessee

The **Family to Family Adult Care Service** in Memphis, Tennessee has experienced remarkable growth from 10 to 80 plus families during its initial three years. Serving persons with physical disabilities, behavioral and mental health challenges, and dementias, and their caregivers, Family to Family uses a person- and family-centered approach, beginning with an initial home visit, addressing global needs in addition to respite, and anticipating the emotional needs of caregivers and care recipients during challenging times. Respite is provided in-home, and may include community outings such as attending faith-based services according to family desires. Training and support are provided to staff in practical nursing skills and relevant caregiving topics as well as through role playing activities that support staff in bringing humor into the homes of the families served. This warm hearted, humanitarian spirit is especially evident in the *80 Plus Program*, in which Family to Family collects oral histories from their clients who are 80 years and older. The program is assembling these stories in a documentary that will allow them to share the wisdom from these elders with others. Visit their [Facebook page](#).

Music Therapy Respite Program
Cleveland Clinic Lou Ruvo Center for Brain Health
Las Vegas, Nevada

The **Music Therapy Respite Program** at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas has elevated an established therapy approach among aging populations by combining it with respite, a person-and family-centered approach, and integrated therapy at no cost to families. Using trained therapists working with care recipients who have Alzheimer's or other dementias to meet individualized therapeutic goals during 90 minute music therapy sessions, and a cadre of carefully recruited, trained, supervised and supported volunteers to support care recipients and families, the Music Therapy Respite Program creates a respite space for caregivers. Caregiver support group options

are also offered while their loved ones' social-emotional and therapeutic needs are addressed through music therapy. These statements from caregivers convey the importance of this program to caregivers and recipients, and to family relationships:

- ❖ *When I see Sally in music therapy, I see my wife, not the Alzheimer's.*
- ❖ *After leaving music therapy, I get my wife back. For the 15 to 20 minute ride home, we sing together in the care and it feels like old times.*

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