State Summaries of Lifespan Respite Grant Activities and Outcomes
Final Reports: FY2017 and FY2018 Grantees
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Summaries from some state grantees were not included in this report because the grantee did not provide information.
Introduction and Acknowledgements

The Administration for Community Living has administered the federal Lifespan Respite Care Program since 2009. When they announce a funding opportunity for states, leaders in the field of lifespan respite across the nation put pen to paper to apply for funding to support their state’s lifespan respite system. In writing, they record the collective aspirations for caregivers and care recipients in their state, consistent with their state’s particular resources, needs, values and beliefs.

The Federal Lifespan Respite Care Program outlines five objectives that state lead agencies must honor should they receive a grant award.

1. Expand and enhance respite services in their state.
2. Improve coordination and dissemination of respite services.
3. Streamline access to programs
4. Fill gaps in services where necessary.
5. Improve the overall quality of the respite services currently available.

These objectives are important in fulfilling the purpose of the Lifespan Respite Care Program – to create coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs.

Approaches to meeting these objectives are by necessity flexible rather than prescribed, allowing individual states to create, shape and refine lifespan respite systems according to their state’s unique circumstances. Across the nation, certain approaches emerge as popular and useful – collaborative partnerships with agencies, programs, and caregivers; no wrong door ports of entry for caregivers to receive services; statewide websites and data bases providing information and access to services; and recruitment and training of respite providers and volunteers to address the workforce shortage. Many grantees may also offer discretionary mini-grants to community and faith-based agencies to expand respite services; volunteer respite options; emergency respite services; and self-directed respite vouchers to help families pay for respite – for example. But each state will have a unique way of designing and carrying out goals and activities related to these.

In the following summaries of the final reports from FY 2017 and FY 2018 State Lifespan Respite grantees, the projects’ outcomes, accomplishments, and successful partnerships are highlighted. Especially noteworthy are the flexibilities grantees introduced in respite voucher programs, mini-grants, and volunteer efforts during the COVID-19 pandemic, and the creative respite and education alternatives that were used to ensure that caregivers were continuously supported. The lessons learned provide an opportunity to discover unique approaches and to begin or continue a dialogue around topics important to you with other leaders across the nation, and with key partners in your own state. The information is also intended to inform policymakers and funders about innovative solutions that are being developed at state and local levels to advance access to respite and caregiver supports at a time when the need is escalating rapidly. From these vital and timely summaries, ARCH hopes to capture best practices in the design and implementation of Lifespan Respite systems and services to guide continued policy and program improvements.

Acknowledgements

ARCH wishes to thank the Lifespan Respite grantees who graciously shared with us their grant proposals, semiannual and final reports that were previously submitted to ACL to meet federal grant requirements. We also want to thank them for taking the time to review the content of their prepared state summaries.

This product could not have been completed without the tireless work of Susan Janko Summers, PhD, ARCH Consultant, who was the principle author of this document. She spent countless hours reviewing the many proposals and reports submitted by the grantees and drafting the summaries of each state’s Lifespan Respite grant objectives, outcomes and activities. ARCH is also grateful to Norma McReynolds for her beautiful graphic design and layout.
### Key Performance Measures

<table>
<thead>
<tr>
<th>North Dakota used process, product, outcome, and cost measures including: enumeration and documentation of an array of training and outreach activities; measures of learning that occurred as a result of participation in training and outreach activities; increases in the use of respite vouchers; costs of activities accomplished to meet stated objectives; and in-kind cost savings realized through partner participation in the statewide voucher respite program.</th>
</tr>
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<tbody>
<tr>
<td>Notable Achievements:</td>
</tr>
<tr>
<td>The grantee produced an educational video that defines respite and discusses the importance of caregivers taking a short break. The video is available for individuals to watch on their own, or for professionals to use when they would like an additional tool to share with caregivers about the importance of getting a short break. In addition to the 2.5-minute video, 30-second television and radio public service announcements were developed. In cooperation with the North Dakota Broadcasters Association (NDBA), the public service announcements aired on television and radio over three months. Public service announcements aired 7,357 times.</td>
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### Key Objectives, Activities and Outcomes

**Objective 1. Increase awareness of existing respite services and resources for caregivers.**

**Notable Performance Outcomes and Awareness Activities**

- Education and training for caregivers were enhanced through the development of the contracts with NDSU Extension, Family Voices, and NRCNAA.
  - Nearly 400 individuals participated in the classes offered through these contracts.
- Aging Services Division contracted with Family Voices to provide financial support for eight Caregiver Cafés for children with special needs. The events included information on the importance of respite and were offered across North Dakota.
  - Prior to attending Caregiver Cafés, 35.29% of participants indicated that they needed “lots of information” or “could benefit from development” in order to feel comfortable sharing information. Following the Caregiver Cafes, 88.89% of participants stated that they “agree” or “strongly agree” they will comfortably share information on caregiving resources.
- Respite as a shared topic increased during the funding period through meetings, conferences, and trainings across North Dakota including: State Plan on Aging Public Hearings; AARP statewide Lunch & Learn and Coffee & Conversation events; the North Dakota formed a Respite Coalition that met quarterly, both virtually and in-person. Membership grew throughout the grant period and included representatives from all areas in the state. The Coalition, including broad representation from stakeholders, worked to promote awareness of available services, and provided regular input for administration, collaboration, and coordination of grant activities.
- The grantee produced an educational video that defines respite and discusses the importance of caregivers taking a short break. The video is available for individuals to watch on their own, or for professionals to use when they would like an additional tool to share with caregivers about the importance of getting a short break. In addition to the 2.5-minute video, 30-second television and radio public service announcements were developed. In cooperation with the North Dakota Broadcasters Association (NDBA), the public service announcements aired on television and radio over three months. Public service announcements aired 7,357 times.
### Key Objectives, Activities and Outcomes

- Dakota Symposium on Aging; college and university training including Tribal colleges; ND Senior Service Provider Association; Title VI Cluster Training event; ND Committee on Aging; ND Partnership program; North Dakota Veterans of Foreign Wars and Auxiliary conference; social workers, discharge planners, and nurses from various hospitals; Home and Community Based Services annual case management training; town hall event entitled *Caregivers Need for Respite Care*; Cass/Clay Senior Coalition; and Alzheimer’s Association support groups.

- In cooperation with the North Dakota Broadcasters Association, public service announcements were aired on television and radio over three months.
  - PSAs aired 7,357 times with a dollar value of $117,567.

- Family Voices continually promoted respite in their weekly e-news and their hard-copy newsletter, and included a presentation on Lifespan Respite Care during an Extended Learning Call.

### Objective 2: Streamline access to respite services through expanded use of the Aging and Disability Resource—LINK (ADRL).

**Notable Access and Expansion Activities**

- A specific “caregiver link” was added to the ADRL website to enhance caregivers’ and professionals’ access to caregiving information and resources across the lifespan.
- The number of calls and visits to the ADRL increased dramatically during the funding period.
- To assist in identifying existing respite resources, an on-line form was developed, making it easier to add respite information to the ADRL website, and assuring compliance through inclusion/exclusion guidelines.

### Objective 3: Explore opportunities, and provide education and training on caregiving and respite care for all ages, particularly in rural and underserved areas.

**Notable Performance Outcomes and Partnership Activities**

- The first-ever North Dakota Lifespan Respite Summit was held, bringing together 88 people from 19 communities.
- Of those attending the Respite Summit, 97.96% reported their knowledge of respite was high or very high after attending the Summit.
- Eight Regional Caregiver Forums were held in rural communities across the state to share general information on caregiving, detailed information on respite, existing respite resources, and Lifespan Respite vouchers.
  - Group discussions on existing respite and supports for caregivers in their local communities were included, and more than 150 individuals from 42 different communities attended.
  - The Forums were covered extensively by local newspapers, and immediately following, a Qualified Service Provider Roundtable event was held in partnership with North Dakota’s Workforce Development Staff to provide attendees with information on being a respite provider.
- A contract with North Dakota State University Extension was in place each year of the grant to offer Powerful Tools for Caregivers classes to caregivers across the Lifespan.
  - Powerful Tools for Caregivers training became available virtually due to COVID-19 allowing rural caregivers to participate more easily. Information regarding the classes is continually disseminated throughout the state by a variety of entities, including NDSU Extension staff, Aging Services Division Staff, additional ND Department of Human Services staff, and members of the ND Respite Coalition.

### Aging and Disability Resource Center Role

The North Dakota State Unit on Aging houses the Aging and Disability Resource Link (ADRL). The ADRL worked to include a wide array of services and agencies in their online database with the goal of having information on services and agencies across the lifespan and for all populations. The ADRL is also updating their site to be more user- and mobile-friendly and focused on ADA compliance and ease of navigation.
Key Objectives, Activities and Outcomes

- Aging Services Division contracted with Family Voices to provide financial support for Caregiver Cafés for caregivers of children with special needs.
- Aging Service Division contracted with the National Resource Center on Native American Aging (NRCNAA) at the University of North Dakota to make the NRCNAA’s Native Elder Caregiver Curriculum (NECC) web-based.
- The NEC’s curriculum provides culturally sensitive education for Native Elder family caregivers.

Objective 4: Develop a voucher program to provide respite services.

Notable Development Activities and Performance Outcomes

- The grantee developed Lifespan Respite Care Grant service forms that were fillable electronically, including signatures. The grantee worked with service partners to problem solve reasons behind a low rate of voucher requests, and worked to change an Emergency Respite focus, to Planned, Unplanned and Emergency Respite, and they more clearly defined the intent of the vouchers.
  - This change dramatically increased the number of applications received and the number of caregivers served.

Program Flexibilities and Supports Introduced in Response to COVID-19

- Through its contract with ND State University Extension, the grantee offered Powerful Tools for Caregivers virtually.
- Changes were made to the Lifespan Respite Care Grant Service Standards to provide additional support to unpaid caregivers during the pandemic, including:
  - Waiving the requirement that the provider cannot reside in the same household as the care recipient.
  - Allowing virtual respite to be utilized if the health and safety of the care recipient could be assured.
  - Making Lifespan respite vouchers available regardless of how much respite the caregiver was receiving from other public funding sources.
Lifespan Respite Grantee Lead Agency: South Dakota Department of Human Services, Division of Long Term Services and Supports

Funding Period: September 1, 2017 to August 31, 2021

Contacts: Lesley Farmen at Lesley.Farmen@state.sd.us

Primary Goal: Improve overall access to respite services for families and other caregivers through provider development and training within the State of South Dakota

Key Performance Measures

Evaluation measures used by the grantee included the following products (marketing materials; website development with training resources for caregivers; and a searchable respite provider directory); survey data (Lifespan Respite Survey). The evaluation also included performance outcomes documented through the enumeration of caregiver referrals and emergency services provided.

Notable Achievements

The Lifespan Respite grant positively impacted the legion of caregivers around the State of South Dakota. The South Dakota Respite Coalition increased public awareness of respite needs and strengthened caregiver advocacy; increased statewide awareness of respite services; provided better responsiveness to the needs of caregivers; and expanded access to respite services by more efficiently directing caregivers to support and services that best suited their specialized needs through a variety of funding options. As a frontier state, special emphasis was placed on better reaching rural and tribal populations.

Key Objectives, Activities and Outcomes

Objective 1. Develop and administer a Lifespan Respite Survey

Notable Products and Performance Outcomes

- To improve access to respite care for families and caregivers, and to inform the Coalition of the respite needs of family caregivers across populations, the grantee created a Lifespan Respite Survey. The grantee drafted a postcard and disseminated it to individuals receiving services through the Title-III National Family Caregiver Support Program. The postcard instructed caregivers to visit a website that linked to the survey. A paper copy of the survey was offered to caregivers with limited access to the internet.
  - Survey responses totaled 139 and indicated that most caregivers were not receiving as much formal and informal respite care as they would like, which contributed to high levels of stress and anxiety. Some caregivers also identified a lack of knowledge about available resources in their community.
  - Survey data were used by the South Dakota Respite Coalition to guide the creation of a website that would educate caregivers and offer more options for respite assistance.

Coalition, ADRC and Community Partners

State and Community Partners

Key partners involved in activities for each grant objective included: the Title-III National Family Caregiver Support Program; the South Dakota Respite Coalition; South Dakota Division of Developmental Disability Respite Care Program and Division of Long Term Services and Supports Respite Care Program, and the U.S. Department of Veteran’s Affairs Respite Care Program.

State Respite Coalition/Organization Role

The foundation of the Lifespan Respite grant was the creation of the South Dakota Lifespan Respite Coalition. Stakeholders
Objective 2: Create a Lifespan Respite Website

Notable Activities and Performance Outcomes

- In November, 2018, the Lifespan Respite website was created. The website provides:
  - a brief overview of what Lifespan Respite is, who it is intended for, and information about the Lifespan Respite grant, the South Dakota Respite Coalition, Dakota at Home (South Dakota’s ADRC), and a Lifespan Respite brochure;
  - respite care options in South Dakota: Division of Developmental Disability Respite Care Program, Division of Long-Term Services and Supports Respite Care Program, U.S. Department of Veteran’s Affairs Respite Care Program;
  - a link to a respite care certification program for caregivers;
  - a link to the respite provider registry – the database housing a list of providers (both agency and individual); and
  - resources for caregivers: a complete learning library and more information about caregiver support programs around the state.

- During the three years since its inception, the Lifespan Respite website was visited 972 times, over 8,000 pages were viewed; 398 downloads were made; and 248 out-links to other resources were navigated.

Objective 3: Construct a Respite Provider Registry

Notable Activities and Performance Outcomes

- To expand and enhance respite availability for caregivers in South Dakota, a respite provider registry was constructed on the Lifespan Respite website. The registry offers information about things caregivers might consider and questions to ask before hiring an agency or independent provider, and contains a link to the State of South Dakota Unified Judicial System for background checks and fair labor standards guide for families. For those looking to become a provider, an application is available on the site.

- At the end of the project cycle, the registry contained 103 agency and 31 individual providers. Long-Term Services and Supports Service Coordinators that provide social work to individuals on the Title III National Family Caregiver Support Program offer the registry as an option for unmet respite needs.

Coalition, ADRC and Community Partners

were recruited from organizations at state and federal levels, business establishments, community partnerships, non-profits, and public caregivers. Coalition members met monthly in order to sustain open communication, inform members of proceedings with the Lifespan Respite Grant, gather thoughts on enhancing respite care services to families and caregivers, and encourage stakeholders to continue personal and professional outreach on behalf of the Coalition. To enhance membership sustainability, Coalition members were directly involved in planning and implementing ongoing activities, including the Lifespan Respite Survey, Lifespan Respite website, Respite Provider Directory, respite provider recruitment, and training development initiatives.

Aging and Disability Resource Center Role

The Lifespan Respite Website links with Dakota at Home, South Dakota’s ADRC, making information about ADRC services available and accessible to South Dakota caregivers.
Lifespan Respite Grantee Lead Agency: **Alabama Department of Senior Services (ADSS)**

**Funding Period:** September 1, 2017 to August 31, 2021

**Contact:** Traci Dunklin at Traci.Dunklin@adss.alabama.gov

**Primary Goal:** Enhance and expand existing respite and support services to family caregivers of children and adults, while developing a policy framework to expand and strengthen Alabama’s current lifespan respite care initiatives.

### Key Performance Measures

The extent to which the stated goal and objectives were reached was documented through increases in respite care options for caregivers of family members with a range of disabilities and diseases; process measures documenting the development and implementation of information resources; and increases in information use. Performance measures included: number of caregivers served; level of satisfaction; number of public education/outreach/advocacy efforts; amount of new information on caregiver resources available; and number of on-line users.

### Notable Achievements

In addition to continuing and increasing respite, trainings, and educational workshops, Alabama’s Lifespan Respite team offered enhanced services to help address caregivers’ emotional, physical, and financial needs from the onset of the pandemic through virtual support groups, web-based training and tools, and individual phone or video conferencing “Care Chats.” The Alabama Lifespan Respite Coalition, in an updated white paper, proposed legislative recommendations to increase public policy awareness, and a legislative framework for strengthening Alabama’s lifespan respite care initiatives.

### Key Objectives, Activities and Outcomes

**Objective 1. Enhance respite opportunities for all family caregivers.**

The Alabama Universal Voucher Program was the primary means to increase respite opportunities, including opportunities for underserved caregivers. Alabama Respite consistently advocated to public, non-profit, faith-based, and corporate entities to partner in funding and expanding the program.

**Notable Performance Outcomes**

- During FY2020 alone, Alabama Respite facilitated delivery of 76,716 hours of self-directed respite to 1,896 family caregivers statewide.
- The Universal Voucher program served 882 unduplicated family caregivers throughout this grant cycle.
- An additional 300 family caregivers, who did not qualify for Medicaid, Alabama Cares/AAA, Veterans Administration, or other agency respite programs, received on average 42 hours of planned respite per year.
- As a direct result of Alabama Respite’s efforts during the grant cycle, nine new contracts were implemented with AAA’s, creating enhanced respite opportunities for aging caregivers.

### Coalition, ADRC and Community Partners

**State and Community Partners**


**State Respite Coalition/Organization Role**

Alabama Lifespan Respite Coalition members, a diverse group of stakeholders, are appointed by the Governor and rotated regularly, with the exception of state
These new contracts reflect increases in the number of caregivers served within local communities and across the state.

- Start-up mini-grants supported expansion of respite day services and start-up funding for two Day Respite Programs annually.
- Alabama Respite staff collaborated with selected projects and committed community stakeholders to provide substantial guidance and assistance in all phases of their individual projects. Staff initiated electronic announcements of available respite day funding to over 3,000 contacts statewide.
- In response to the pandemic, Alabama Respite contracted with all 13 Area Agencies on Aging (AAAs) to provide respite relief across the state, ensuring that caregivers of older adults and persons with chronic disabilities received a break from especially stressful caregiving responsibilities and circumstances.

**Objective 2:** Increase and expand existing support services to caregivers utilizing existing and expanded trainings and educational opportunities.

**Notable Partnerships, Expansion Activities, and Performance Outcomes**

- Educational and public awareness activities increased during the funding period.
  - From September, 2018 through February 2019, 56,500 contacts were made through phone, email, social media, and website visits.
- To inform the public about respite and caregivers, Alabama Respite conducted Lunch-n-Learns at local programs and agencies, and short trainings on topics including the importance of respite and caregiver wellness.
  - Lunch-n-learn trainings were delivered in 41 different settings during a six-month period, and a total of 16 workshops were conducted through the grant cycle.
- An array of well-attended caregiving opportunities were offered throughout the state including, for example: the Helping Those Who Care (HTWC) assistive technology training for caregivers of family members with age-related disabilities (this training provided respite vouchers that allowed caregivers to attend trainings); and multiple trainings on Covid-related topics such as mental health, quarantining routines, and technology use.
  - The HTWC goal for onsite statewide training sessions was set at 10. This goal was exceeded with a total of 17 onsite trainings conducted.
  - One hundred, forty-four sessions of technical assistance were conducted via phone, email, and virtually with an AT specialist.
- Respite related training focused on evidence-based and evidence-informed caregiver interventions, including Caregiver Stimulation Training, a hands-on awareness and education program. New partnerships were created with Jacksonville State University, Alabama A&M University, and University of North Alabama to conduct training for potential future caregivers and providers.
- Through these partnerships with programs and agencies, Alabama Respite in turn learned about local and program needs for emergency respite, educated agency “gatekeepers,” and facilitated referrals for needed services, thereby optimizing Objective 1, enhancing respite opportunities, in addition to increasing respite awareness.

**Aging and Disability Resource Center Role**

Alabama’s ADRC makes respite information and support available by phone on an established toll free number. The toll-free number and related information is publicized and available through community service providers, case managers, hospital discharge planners, and other agencies working with ADSS and Alabama Respite. ADRC uses a Universal Intake Form and conducts a screening to identify benefits, services, and the need for additional caregiver assistance.

**Coalition, ADRC and Community Partners**

Agency representatives. Coalition members actively participate in Alabama Respite activities, including a subcommittee to assist in reviewing and updating respite provider listings for the interactive online provider database. The Coalition partners with the Caregiver Taskforce, ADSS, and Alabama Respite to support and coordinate opportunities for family caregivers to educate public policy makers and communities about the growing number of caregivers and the complex issues they face.
Key Objectives, Activities and Outcomes | Coalition, ADRC and Community Partners

**Objective 3:** Strengthen advocacy and education to public officials and policymakers to encourage implementation of expanded HCBS policies to include caregivers and provide funding for formalized, sustainable respite and support services for caregivers.

**Notable Partnerships, Activities, and Products**

- Alabama Respite partnered with Respite Coalition members and the Alabama Department of Senior Services to launch a family caregiver and respite provider 10-year follow-up statewide online survey in order to learn about caregiver support services in the state. Data collected were used to inform and support additional projects and legislative work.
- An updated white paper entitled *Your Voice Matters—The Impact of Family Caregiving in Alabama* included up-to-date recommendations for state legislators.
  - Alabama Respite staff followed-up distribution of the white paper with personal phone calls to key legislators.
  - The white paper was available electronically, on the Alabama Lifespan Respite website, and in hard copy.
- Live community town hall forums pre-pandemic, and virtual meetings during the pandemic, were conducted to allow family caregivers to hear from state and federal leaders, to ask questions and receive answers, and to learn how to best care for their loved ones.

**Program Flexibilities and Supports Introduced in Response to COVID-19**

- Alabama Respite staff participated in demonstrating and creating new approaches to caregiver education opportunities and resources, including:
  - Short video tutorials on how to use the internet, how to complete a voucher application, and importance of maintaining routines during quarantine.
  - Series of pre-recorded and live-stream caregiver education and virtual BREAK events.
  - Collaborative partnership with the Colorado Respite Coalition for Facebook live presentations on mental health wellness.

For more information, contact ARCH at (703) 256-2084
Lifespan Respite Grantee Lead Agency: Arizona Department of Economic Security (ADES), Division of Aging and Adult Services (DAAS)

Funding Period: September 1, 2017 to August 31, 2021

Contacts: Lita Nelson at litanelson@azdes.gov and Jutta Ulrich at Jutta@azcaregiver.org

Primary Goal: Enhance current statewide respite services to provide prepaid community-based choices – fulfilling the unmet need for caregivers of low-income families by providing access to transportation and a variety of disease –, special needs –, and culturally-specific state licensed adult day health centers.

Key Performance Measures

The grantee measured changes in caregiver wellbeing and expansion of the Lifespan Respite Program through strategic outreach activities. In Grant Year 2, the grantee integrated a shortened Caregiver Assessment Tool (CAT) to capture pre and post stress indicators; increase of activities related to self-care; and other outcomes related to utilizing respite services. To create a seamless system for coordinating services, the Area Agencies on Aging (AAAs) and the Arizona Caregiver Coalition (ACC) continue to use the State’s client database, Division of Aging and Adult Reporting System or DAARS, to record demographics and service use. The Grantee and the ACC continued to develop outreach to underserved populations in Arizona by including Spanish language materials; increasing public visibility by participating in community events and presentations; and continuing to share the toll-free number to access caregiver respite and resources. The ACC continued to provide a monthly report to capture incoming caregiver contacts for the Lifespan Respite Program.

Notable Achievements

The collaboration between DAAS and the ACC continues to help identify gaps in respite care services and in recognizing underserved populations in Arizona. One notable achievement is the grantee partnered with the state Division of Developmental Disabilities (DDD) to identify and serve families not eligible to receive respite services through other state and federally funded respite programs. The second notable achievement is the grantee offered respite vouchers throughout the State where respite care services or providers were not available through AAAs or other community-based organizations. The voucher program was especially utilized during the COVID-19 pandemic as an alternative to Adult Day Health Centers (ADHCs). The third notable achieve is the grantee and the ACC convened an Advisory Committee that included members or participants from the AAAs, DDD, several ADHCs, home care agencies, the Veterans Administration, and Adult Protective Services, to develop a collaborative foundation for the Arizona Respite Network.

Key Objectives, Activities and Outcomes

Objective 1. Increase awareness, knowledge and visibility of the Day Center Respite Program.

Notable Public Awareness and Outreach Activities

- To expand information about respite care, respite services, and ADHCs, the ACC participated in outreach events and community health fairs and made presentations to a variety of organizations and community groups.
- Information about ADHCs was added to the ACC website, with a page on the website dedicated to participating ADHCs.

Coalition, ADRC and Community Partners

State and Community Partners

The State Unit on Aging, Arizona Department of Economic Security (ADES), Division of Aging and Adult Services (DAAS), is the Lifespan Respite Grantee. DAAS is the administrative and fiscal arm of the grant and advises on policy development, program innovation, and carries the fiscal responsibilities for all activities related to
Newsletter articles and Facebook posts also promoted the benefits of caregiver respite and of ADHCs.

Flyers for the day respite program were developed and used in mailings, with partner organizations, health fairs, and posted on the ACC website.

- In 2019, a Spanish language version of the flyers was created and disseminated.

Objective 2: Expand coordination of services by continually expanding adult day health center partnerships.

Notable Partnerships, Expansion Activities, and Performance Outcomes

- Recognizing underserved populations in Arizona, the grantee partnered with the state Division of Developmental Disabilities to identify and serve families not eligible to receive respite services through other state and federally funded respite programs.
- During the COVID-19 pandemic, the ACC worked closely with the ADHCs that closed and offered the voucher program to impacted caregivers. When or if the ADHC reopened, some caregivers reverted to the ADHC respite.
- The ADES-DAAS contracted with the ACC to coordinate activities for the Lifespan Respite Grant, including outreach, intake and assessment of caregivers, authorization of services, and reporting.
- During the initial phase of the Lifespan Respite Program funding, a total of 18 ADHCs participated and referrals for respite services were made to 16 of the 18 centers.

Objective 3: Increase access to respite for most vulnerable caregiver populations.

Notable Partnerships and Expansion Activities

- A respite voucher program was added in 2020 to increase respite care options for caregivers living in geographically rural areas that did not offer ADHC sites.
- The respite voucher program was made available to caregivers impacted by the COVID-19 pandemic as ADHCs closed.
- A voucher program was offered by the Area Agency on Aging, Region One, Inc. as the “Friends and Neighbors” program, allowing families to select their own respite providers and receive reimbursement. Noting that no other AAA program in the state offered a reimbursement or respite voucher program, the ACC recognized the success of the Friends and Neighbors Respite Program and the need to offer respite care options statewide.
- A second AAA, the Pima Council on Aging, added a respite voucher program to its services, modeled on the voucher programs offered by the Area Agency on Aging, Region One, Inc. and the Lifespan Respite program.
- The AAAs in Arizona and the ACC continue to work collaboratively to ensure caregivers are supported by each other. The AAAs send the ACC referrals if they are experiencing wait lists for case management or respite care services.

Objective 4: Disseminate program results.

Notable Performance Outcomes

- The DAARS database ensures that the AAAs and the ACC may cross-reference respite care services, input client demographics, complete assessments, authorize services, input enrollment for services, report utilization, and track expenditures.
- Evaluation data were collected and disseminated to document grantee activities and demonstrate caregiver outcomes.
Key Objectives, Activities and Outcomes

- During the grant period from September 2017 to June 2021, a total of 249 unique caregivers were served with ADHC services, with 34 caregivers receiving a second service.
- During the grant period from September 2018 to September 2020, 55 caregivers received respite vouchers.
- Hours of Adult Day Health Center services provided during the funding period totaled 18,985.
- Hours of respite provided through vouchers during the funding period totaled 51.
- The CAT was used to assess self-perceived stress levels experienced by caregivers pre- and post-respite services.
- Survey results show that for both respite programs, nearly twice as many caregivers reported reduced stress levels after receiving respite services. Voucher clients also reported a reduction of high stress levels, although ADHC clients did not see a large reduction in perceived stress.
- Caregivers reported a decrease in feelings of sadness, anxiety, or nervousness after having used respite.
- Caregivers reported an increase in time available to them to engage in enjoyable activities, from 6% of caregivers prior to receiving respite, to 52% of caregivers after using respite.
- Caregivers overwhelmingly reported that the respite service benefitted them and made their life easier.

Program Flexibilities and Supports Introduced in Response to COVID-19

- Arizona had added a voucher option in year 3 of the grant, 6 months prior to COVID-19 forced closures. Allowing family caregivers to choose friends, family members or neighbors as respite providers proved advantageous for families who increasingly were afraid to let outsiders into their homes.
Lifespan Respite Grantee Lead Agency: **Colorado Department of Human Services, State Unit on Aging (SUA)**

Funding Period: September 1, 2017 to August 31, 2021

Contacts: Amy Harris at amy.harris@state.co.us and Todd Coffey at todd.coffey@state.co.us

Primary Goal: **Colorado’s overriding goal was to build upon the Colorado Respite Care Program’s work in previous grant periods to strengthen Colorado’s respite and caregiving infrastructure and increase access to resources and supports.**

### Key Performance Measures

Data collected by the grantee documenting the extent to which objectives were achieved included:
- number of families served;
- number of respite hours provided;
- number and types of meetings held;
- number and types of products developed;
- number, types, and sustainability of partnerships established;
- scope of website and social media presence;
- number of inquiries from families and partnerships.

The Colorado Respite Care Program (CRCP) also partnered with an external evaluation team in 2019 to better understand barriers to access families faced when participating in the voucher program. The evaluation identified areas in the award process that the CRCP was able to adjust to simplify steps for families, which increased efficiency and accessibility.

### Notable Achievements

The CRCP made significant enhancements to its website, including the addition of mobile responsiveness and development of user accounts to save favorites and submit content, such as upcoming trainings and resources. As part of the Respite Care Task Force project, the CRCP recreated its Respite Locator, now called the Online Resource Finder, to include trainings and events, educational materials, and broader resources, as well as respite providers. The Online Resource Finder features more narrow search options to increase user friendliness, and a resource hotline, available to the public and listed at coloradorespitecoalition.org.

### Key Objectives, Activities and Outcomes

**Objective 1. Colorado will have a stronger respite infrastructure, which builds on the growth of the previous six years.**

**Notable Partnerships and Infrastructure Activities**

- The Colorado Respite Care Program (CRCP) led new regional efforts in southwest and southeast Colorado, and supported and reengaged groups in Northern and Southern Colorado, the Denver Metro, and Summit and Mesa counties. These partnerships strengthened Colorado’s respite infrastructure, helped CRCP identify gaps in services across the state, and allowed recognition of successes as well as collaboration to promote respite awareness.

- The CRCP leveraged State General Funds and the At Risk Persons Surcharge funds to support respite care services, and caregiver training and education. Funds for direct care services are designated for underserved families, most of whom do not have access to alternative funding sources other than private pay.

### Coalition, ADRC and Community Partners

**State and Community Partners**

Key partners include: Chronic Care Collaborative, MindSource, the Colorado Department of Human Services (CDHS) Brain Injury Program, Aging and Disability Resource Centers (ADRC), Colorado Respite Coalition, which is a program of Easterseals Colorado, and regional respite coalitions.

**State Respite Coalition/Organization Role**

The Colorado Respite Care Program (CRCP) began in 2011 with a federal lifespan respite grant which focused on laying the foundation for a more streamlined way of supporting families. The CRCP provides resources.
**Key Objectives, Activities and Outcomes**

- The CRCP partnered with the Bell Policy Center to explore the potential role of private insurance in covering the costs of respite care services. Although the report showed that insurance coverage is rare, the efforts highlight opportunities for future collaboration.

**Objective 2: Family caregivers in Colorado will be able to more easily access respite resources and supports.**

**Notable Performance Outcomes and Infrastructure Activities**

- The family respite voucher program provided increased access by utilizing a new source of funding to operate a small secondary voucher program for adoptive, foster and kinship families.
- The family respite voucher program provided more than 15,000 hours of respite, helping 456 Colorado families.
- CRCP staff and one partner led Stress Busting for Family Caregivers and Stress Busting for the Caregiving Professional classes.
- Two additional CRC staff members completed the Stress Busting courses and plan to become master trainers, and the CRCP hosted a training session to increase the number of class facilitators in the state.
- The CRCP held one in-person and one virtual conference for faith communities to offer resources about caregiving across the lifespan and to share a faith community toolkit.
- Building upon earlier efforts to engage local employers, the CRCP published the Caregiving-Friendly Workplace Toolkit, available in hard copy and electronically to the public. CRCP staff and partners hosted lunch and learns about caregiving wellness and resources and presented the toolkit to local human resources and employee wellness groups.
- The CRCP made significant enhancements to its website including the addition of mobile responsiveness, a redesign, and development of user accounts to save favorites and submit content such as upcoming trainings and resources. The website can also be translated into multiple languages. As part of the Respite Care Task Force project, the CRCP recreated its Respite Locator, now called the Online Resource Finder, to include trainings and events, educational materials, and broader resources, as well as respite providers. The Online Resource Finder features narrowed search options to increase user friendliness. A resource hotline is also available to the public on the website.

**Program Flexibilities and Supports Introduced in Response to COVID-19**

- The CRCP:
  - Created an online COVID-19 caregiving resource list.
  - Focused on sharing resources about basic needs, self-care, mental health, and creative ways to access respite.
  - Distributed self-care toolkits.
  - Offered scholarships for the NextStep online COVID-19 caregiver training.

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**Coalition, ADRC and Community Partners**

to caregivers caring for individuals of all ages and care needs across Colorado, including providing information, resources, and referrals to family and professional caregivers; distributing respite vouchers to caregivers with limited access to respite; administering grants to agencies to increase access to respite care services statewide; collaborating with organizations that provide training on respite and caregiver supports; and facilitating training and educational opportunities for respite providers, caregivers, and employers across Colorado.

**Aging and Disability Resource Center Role**
The State Unit on Aging (SUA) oversees and coordinates the ADRC program. The CRCP worked with ADRCs by sharing respite and caregiver resources to expand the number of resources available to families. The CRCP partnered with ADRCs to promote its caregiving awareness campaign and to share their hotline with people seeking resources.

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For more information, contact ARCH at (703) 256-2084

archrespite.org

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Lifespan Respite Grantee Lead Agency: **Idaho Commission on Aging (ICOA)**

**Funding Period:** September 1, 2017 to August 31, 2021

**Contact:** Lynn Fyanes at Lynn.Fyanes@aging.idaho.gov

**Primary Goal:** The Idaho Commission on Aging’s (ICOA) project goal was to expand access to respite services for family caregivers and strengthen Idaho’s policy framework to support and sustain the respite program.

### Key Performance Measures

Idaho Commission on Aging/Idaho Caregiver Alliance documented: numbers of Summits; Annual Caregiver Conferences; Powerful Tools for Caregiver Classes; and contracts with seven community respite providers. Numbers served by community respite providers were regularly collected and demonstrated a steady increase in caregivers served over the grant period. In conjunction with the Alzheimer’s Disease and Related Dementia grant, Boise State University-Center for the Study of Aging evaluated the impact of the Consumer-Directed Lifespan respite (CDR) program. (See Objective 4.)

### Notable Achievements

Idaho was one of six states selected to participate in the Center for Health Care Strategies Helping States Support Families for an Aging America Initiative. Following their selection, the Idaho Commission on Aging and the Idaho Caregiver Alliance (ICA) participated in a collaborative to address identified needs at state and national levels to advance innovations that support family caregivers. As part of the initiative, Idaho has committed to work with Medicaid to develop an online resource center of respite and other caregiver and family supports, accessible by families, health insurers of people dually eligible for Medicaid and Medicare, and community-based organizations.

### Key Objectives, Activities and Outcomes

**Objective 1.** Coordinate and strengthen lifespan respite systems at the state and local levels.

**Notable Partnerships and Systems Strengthening Activities**

- The ICOA developed a State Strategic Plan in 2018 that includes a commitment to implement the Action Plan, sustain the ICA, and continue to develop and enhance lifespan respite. Actionable steps demonstrating that commitment include continued work with policymakers to improve social, financial, and supportive services environments for caregivers across the lifespan.
- The ICA convenes quarterly, develops respite workshops for three state and regional conferences each year.
- In 2017, Idaho conducted a Registry study that concluded: “A more successful method of connecting family caregivers to providers seems to involve personal interaction, either by calling a resource careline or by word-of-mouth.” This led ICA to Medicaid Follows the Person Family Caregiver Navigator Pilot Program.
<table>
<thead>
<tr>
<th>Key Objectives, Activities and Outcomes</th>
<th>Coalition, ADRC and Community Partners</th>
</tr>
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<tbody>
<tr>
<td>ICA coordinates with the ICOA to develop a comprehensive list of resources in addition to the web-based site: <a href="http://FindHelpIdaho.org">FindHelpIdaho.org</a></td>
<td>representing the private and public sectors who work to increase public awareness about the value of family caregivers to healthcare teams and to inform providers about resources and supports available to caregivers, and how to access them.</td>
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**Objective 2: Provide innovative and emergency respite services to family caregivers.**

**Notable Performance Outcomes**

- Over a three-year period, seven community partners provided respite.
  - The number of caregivers receiving respite services from respite partners totaled more than 1,900.
  - During the funding period, the number of caregivers receiving respite more than doubled from 400 in 2019 to more than 800 in 2021.
- IOCA contracted with Southwest Area Agency on Aging/AAA III to implement Consumer-Directed Lifespan Respite (CDR) and caregiver supports system development to establish best practices for Idaho’s Family Caregiver Support Program.
  - While establishing processes, procedures, and training protocols, AAA III provided consumer-directed outreach and respite to 119 caregivers using a $600 every six months/$1,200 a year voucher program.
  - During September 2020 - August 2021, lifespan enhancement activities supported respite services to more than 190 caregivers across Northern, Southern, Southwest and Southeastern Idaho, rural and frontier areas, with implementation plans to expand into North Central and Eastern Idaho in 2022.
  - An evaluation of the CDR Program showed statistically significant improvements in caregivers’ perceived ability to pay for services; perceived ability to cope with caregiving stress; perceived ability to manage burnout; and perceived ability to care for loved one at home.
- An evaluation of the Family Caregiver Navigator Pilot Program showed that:
  - Caregivers’ confidence increased in their ability to identify actions to reduce stress; ability to access resources from their care plan; make positive changes in their role as caregiver; and communicate needs as caregiver.

**Objective 3: Increase the level of knowledge and professionalism in respite care by providing training to caregivers, providers, and volunteers.**

**Notable Performance Outcomes**

- During the funding period, ICOA/ICA:
  - Held two Lifespan Respite Caregiver Summits.
  - Held four Annual Caregiver Conferences.
  - Instituted Powerful Tools for Caregiver classes.
  - Made Idaho lifespan respite information and tools accessible on the ICOA, ICA, and seven community respite providers websites.
  - Implemented a consumer-directed lifespan respite pilot.
  - Piloted the Family Caregiver Navigator through the Idaho Department of Health and Welfare (IDHW) Medicaid Money Follows the Person Program.
- These initiatives increased the number of caregivers accessing respite information and services.
Objective 4: Enhance access to respite care information by establishing new information access points in addition to the Area Agencies on Aging/Aging and Disability Resource Centers (AAAs/ADRC).

Notable Outreach and Education Activities

- The ICA regularly sends out quarterly newsletters/toolkits with respite care messaging, training, and presentations for distribution statewide through local channels utilizing the ICA network.
- In addition to providing tips for organizations on how to identify and encourage caregivers to seek respite, toolkits equip access points like the AAA/ADRCs, 211 Careline, Idaho Parents Unlimited, IDHW Navigators and Regional Medicaid Units, the Idaho Healthcare Association (private long term care providers), Community Partnerships of Idaho, the MS Society, Critical Access Hospitals (CAH), Idaho school districts, and Easterseals of Idaho with essential respite information for lifespan caregivers.

Program Flexibilities and Supports Introduced in Response to COVID-19

- All providers remained flexible and creative and adjusted their programs by offering, family-fun drive-up activities and vouchers, virtual and telephone call check-ins, and more 1:1 counseling and education.
- To assist with making appropriate volunteer/family respite-care matches, vaccination status was added to all intake forms to ensure all families and volunteers were matched safely and in accordance with preference.

For more information, contact ARCH at (703) 256-2084
archrespite.org
Lifespan Respite Grantee Lead Agency: **Massachusetts Department of Developmental Services (DDS)**

Funding Period: September 1, 2018 to August 31, 2022

Contacts: Amy Nazaire at amy.nazaire@mass.gov

Primary Goal: Increase the state’s capacity to serve individuals eligible for state agency services and the wider constituency who would benefit from respite.

### Key Performance Measures

The grantee identified the following four measurable objectives in support of their primary goal, and collected data according to those objectives.

1. Increased awareness by families on how to access respite services.
2. Increased number of qualified respite providers.
3. Shared strategies to develop and promote respite services across state agencies.
4. Track availability and utilization of respite provided by state agencies.

To measure cross agency collaboration (see: State and Community Partners and Notable Achievements), the grantee used the Levels of Organization Integration Rubric (LOIR) (Woodland, 2012).

### Notable Achievements

ForHealth Consulting (formerly Commonwealth Medicine), a division of the University of Massachusetts Chan School, served as training and evaluation coordinator during the grant period, supporting the lead agency’s efforts to support both access to respite provider training, and to respite services. In a study on state funded respite policies and programs, ForHealth Consulting identified the need to collaborate across state programs and agencies to improve respite access, improve tracking systems to measure respite service utilization, and to address workforce issues. These studies guided subsequent respite systems management and sustainability planning.

### Key Objectives, Activities and Outcomes

**Objective 1. Increase awareness by families on how to access respite services.**

**Notable Products and Performance Outcomes**

- The grantee developed a Family caregiver video as a vital tool to inform and support family members caring for a loved one. [https://youtu.be/MChah5Pqtns](https://youtu.be/MChah5Pqtns)
  - The video was used to inform and support family caregivers in their caregiver roles, helping them to identify as caregivers, understand the benefits of respite, and access respite resources through MassOptions (free referral hotline) and Rewarding Work (respite referral directory).
  - MassOptions offers a toll-free call center available to everyone regardless of income. Offering multiple languages, family caregivers can connect with a live person, Monday–Friday from 9a–5pm. MassOptions also offers a fully accessible, multi-lingual website (www.massoptions.org), so caregivers can search for services and supports any day or time. There is also an online chat option for caregivers who prefer text messaging.

### Coalition, ADRC and Community Partners

**State and Community Partners**

A strategic alliance, the State Action Group, worked to achieve and maintain a level of collaboration necessary to produce effective and sustainable change by aligning state respite program descriptions, identifying eligibility gaps, streamlining tracking, and accessing funding to support respite programs across the Commonwealth.

State agency members of the State Action Group included program leads from the Executive Office of Health and Human Services, Department of Developmental Services (DDS), Department of Mental Health...
**Objective 2:** Increase number of qualified respite providers.

**Notable Expansion Activities and Performance Outcomes**
- To increase the pool of trained respite providers, an interagency respite training subcommittee was established and tasked with identifying and recommending a list of training core competencies. The final subcommittee recommended 12 core competencies to guide training of future, diversified groups of respite providers.
  - The competencies were shared with the ARCH Respite Work Group to inform the National Academy for State Health Policy (NASHP)/Respite Care Association of Wisconsin (RCAW)/ARCH provider training.
- Individuals seeking respite worker employment were provided access to free, quality, online training through Rewarding Work, Inc.
  - During the first quarter of 2022, a total of 39 people registered for the training, and eight (21%) completed the training.
  - Post training, individuals could post their availability on the Rewarding Work Directory.
  - Family caregivers were informed of the supply of respite workers and could post their need for respite services to the Rewarding Work Directory.

**Objective 3:** Share strategies to develop and promote respite services across state agencies.

**Notable Partnerships and Expansion Activities**
- Throughout the funding period, the MA Lifespan Respite Program (MLRP), comprised of the State Action Group, Commonwealth Medicine, a division of the University of Massachusetts Chan Medical School (CWM), and Rewarding Work, Inc., aimed to streamline access to respite and maximize opportunities to share information, resources, and lessons learned with the Massachusetts Aging Disability Consortia/No Wrong Door and the provider community. (Rewarding Work, Inc. conducts ongoing recruitment of respite workers, offers online respite training, and maintains the state’s Respite Directory.)
  - Through strategic planning led by the grantee and accomplished by the State Action Group, all state agencies are now included in the MassOptions NWD/ADRC referral system.
  - To provide fundamental knowledge to all state respite program services, the MLRP worked collaboratively with a ForHealth Consulting training development expert to develop a one-hour, online interagency respite training, the Massachusetts Family CARE: Helping Families Access Respite Essentials (MA CARE).
    - The MA Care online training is available to Massachusetts agency staff and other professionals working directly with families needing a break from the ongoing demands of caregiving.
    - In the final year of the grant, over 150 Options Counselors participated in a three-hour webinar that included the one-hour MA CARE Online Training, followed by interactive breakout sessions.
    - Access to the MA Care training is available on the MA Executive Office of Elder Affairs Learning Management System, [www.biplearning.org](http://www.biplearning.org). Training includes a downloadable catalogue of respite resources for professionals working with families in need of respite.
  - All state programs and community providers were informed of the Rewarding Work Directory and of national online respite training on the Rewarding Work website.
**Objective 4: Track availability and utilization of respite provided by state agencies.**

**Notable Performance Measures**

- The grantee sent an electronic survey to eight state program managers (members of the State Action Group). All programs (100%) responded providing the following baseline information on which strategic planning activities (see Objective 3) were based.
  - Baseline data indicated that although all regions of the state supported regional respite programs, 75% could not report readily accessible data about the number of families receiving state funded respite or the costs incurred.

- The grantee worked to reduce the risk of duplication of efforts and increase the promotion of existing programs by working with state agency leaders to conduct a SWOT analysis of the current state of the respite system, and to identify gaps and barriers existing in the system.

- Based on this assessment and collaborative planning, the grantee and partners implemented strategies to enhance and expand the current state respite referral and tracking system.
  - Through the MassOptions program, all state agencies are afforded access to ongoing respite referral data.
  - Enhancements to the MassOptions program allow the state to track:
    - Family caregivers’ demographics such as, gender, age range, and zip code;
    - Requests for respite by type (in-home, out-of-home, planned, emergency);
    - The date of the request and referral; and
    - The referral agency (state or community provider).

**Program Flexibilities and Supports Introduced in Response to Covid-19**

- The MLRP respite training pilot scheduled for 2020 at locally based community colleges was cancelled due to the pandemic. To address this challenge and keep this important initiative alive, the MLRP project director participated in an expert working group with the ARCH National Respite Network and Resource Center, and met regularly to provide input and expert consultation toward the development of a national online respite training.
  - Outcomes of the MLRP training subcommittee were shared with expert workgroup and a national online training was made available.
  - Massachusetts Rewarding Work volunteered to serve as a pilot site, promoting free online training for respite workers.
Lifespan Respite Grantee Lead Agency: **Montana Department of Public Health and Human Services (DPHHS)**

**Funding Period:** September 1, 2018 to August 30, 2022

**Contacts:** Kerrie Reidelbach at KReidelbach@mt.gov and Patrick Kelley at patrick.kelley@mt.gov

**Primary Goal:** Provide sustainable respite services and related supports that are easily accessible to and affordable for family caregivers of children or adults with special needs.

### Key Performance Measures

The grantee evaluated progress on the four objectives stated below over six month implementation phases. The Executive Committee to the grant met weekly and revised the work plan as needed (particularly important during the pandemic). The grantee collected: numerical and demographic data on caregivers and recipients using the state respite voucher program; the health or disability status of care recipients; hours of care provided; employment status of caregivers; and ease of receiving financial assistance for respite. The grantee also collected data using surveys and interviews as part of ongoing program evaluation. Caregivers reported being better able to support loved ones; maintain their own mental, emotional, and physical health; hold down stable work; and contribute to their communities in other meaningful ways.

### Notable Achievements

After surveying the landscape of respite services in Montana, the grantee identified significant unmet need for respite among Montana caregivers. Barriers to respite utilization included restrictive income, resource, or categorical eligibility criteria. Locating a quality, accessible respite provider they trusted was also a barrier for caregivers. To address these barriers and serve family caregivers, Montana launched the Lifespan Respite Voucher program, a self-directed program that allows caregivers to hire someone they already know and trust to spend time with their loved one and provide the primary caregiver with time away from caregiving. Vouchers used totaled 1,214 during the reporting period.

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### Key Objectives, Activities and Outcomes

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<thead>
<tr>
<th>Objective 1. Offer training to family caregivers and potential respite providers.</th>
<th>Notable Partners, Activities, and Performance Outcomes</th>
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<tr>
<td><strong>Notable Partners, Activities, and Performance Outcomes</strong></td>
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<tr>
<td>• The grantee partnered with Montana State University Extension Office and the Montana Geriatric Institute to offer Powerful Tools for Caregivers train-the-trainer sessions across the state to support localized in-person training options.</td>
<td>• The grantee created a series of respite provider education and recruitment events that could be designed and offered regionally.</td>
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<td>• Eighteen persons received training.</td>
<td>• The grantee also provided training for 96 individuals who work for the Area Agency on Aging as ADRC information assistants and/or SHIP Counselors.</td>
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### Coalition, ADRC and Community Partners

**State and Community Partners**

In addition to those ongoing partnerships noted under each objective, the grantee coordinated with the Alzheimer’s Disease and Related Dementia (ADRD) Caregiver Support Committee to discuss potential training available to expand statewide respite providers, and the grantee attended all ADRD Workgroup meetings. The grant Project Manager served on the ADRD executive committee and co-
A planning event brought together 24 coalition members and teams from multiple cities from around the state to Helena to learn about lifespan respite resources available for caregivers and respite providers.

Each team began creating plans for localized events in their region designed to educate the public about the Lifespan Respite program and recruit and train respite providers.

**Objective 2:** Develop a registry of trained providers utilizing the ADRC Resource Directory.

**Notable Partners and Expansion Activities**
- The grantee developed protocol for adding trained respite providers to the ADRC Resource Directory, and in preparation for the new website and database, the old website was evaluated by the coalition and edits were made to streamline use.
- During the funding period, a new data collection system was established and updates are ongoing.
  - The system integrates four different databases the Office on Aging uses, tracks 34 different services, collects a variety of demographic information, makes entering and updating information easier, standardizes language for entering data, and provides the ability to group and view information for different demographics in order to provide a better picture of who is receiving respite.
  - As resources are identified, they are periodically added to the directory according to a maintenance schedule.

**Objective 3:** Support outreach efforts to best educate caregivers and providers about Lifespan Respite.

**Notable Partnerships and Outreach Activities**
- The grantee developed six new PSAs to help recruit respite providers and inform the public about respite.
- The PSAs showed respite providers talking about their experiences caring for an individual. Additional PSAs were intended to educate caregivers and referral sources about the voucher program.
- PSAs resulted in additional referrals from professionals who reported seeing the TV ad or hearing the radio ad.
- The grantee developed respite commercials for two TV shows per year with Aging Horizons film staff. The grantee also participated in a Healthy Living Program that was filmed and aired. The program shared information about respite needs and the Lifespan Respite voucher program – what it is, how to access it, and the importance of respite.
- The grantee redesigned outreach materials including a Lifespan Respite Voucher Referral Packet, making the referral process clearer and easier to use for referral sources.
- The grantee produced a new Respite Provider recruitment brochure, application, and background check form to find and recruit interested individuals to become respite providers and register on the ADRC database.

**Objective 4:** Continue education efforts of policy decision makers to secure funding for the Lifespan Respite Program.

**Notable Performance Measures**
- The grantee met with key Montana House of Representatives members who, through personal experience with the need for respite, valued respite services. House members chaired the caregiver subcommittee. The grantee worked with the broad faith-based community to recruit volunteers to complete training available on the respite registry and to gain representation from faith-based organizations on the Lifespan Respite Coalition.

**State Respite Coalition/Organization Role**
Early in the grant cycle, the grantee paid particular attention to reorganizing the Coalition’s committee structure, determining how and where the Coalition could support the Lifespan Respite Program, and assigning tasks from the work plan. The Lifespan Respite Coalition met quarterly to discuss educational activities, maximize training opportunities, suggest updates to the website and data systems, weigh in on the sustainability strategy, and develop the “Building a Better Network for Lifespan Respite” events.

The grantee also worked to diversify the Lifespan Respite Coalition as a statewide advisory body made up of representatives that could speak to the needs of caregivers, care recipients and respite providers; advise development of additional caregiver supports and public messaging; help with recruitment of respite providers; refer caregivers to the voucher program; and plan for the long-term sustainability of Lifespan Respite infrastructure in the state.

**Aging and Disability Resource Center Role**
Data collection related to Montana’s registry of trained respite providers (Objective 2) used Capstone, the primary database for the AAA network in Montana. Transition to this system and ongoing work towards integration provided the opportunity to reach out to the AAAs and their partners to promote Lifespan Respite.
Key Objectives, Activities and Outcomes

offered suggestions, including gathering a range of data on the benefits of respite and additional needs of the population using respite, which could be used in designing potential legislation moving forward. They also recommended speaking with decision makers in health and human services to get a handle on current and expected funding and to discuss the potential to unify respite programs currently offered through multiple state programs that vary in accessibility and efficiency.

- The grantee followed committee work in the Montana Legislature related to respite and weighed in at relevant hearings over the course of the grant.
- The grantee met with an Administrator for Montana’s DPHHS to discuss the potential of developing a plan to fund respite through the budget. Talking points to utilize with decision makers were developed and the partnership was enhanced. The administrator has since been attending coalition meetings.
- The grantee compiled data on respite use across the state in order to better understand patterns of use, and to inform planning and conversations with decision makers.
- The grantee held a focus group with coalition members on potential respite models and interventions they could see being effective, and began interviewing caregivers to learn about the benefits of lifespan respite in Montana and potential ways to improve the Lifespan Respite program.
- As part of that interview, caregivers were asked if they would be willing to write or testify to the legislature to build a bench of people willing to speak to the value and utility of the program.

Program Flexibilities and Supports Introduced in Response to Covid-19

- Realizing that the COVID-19 pandemic created a significant need to pivot the respite program in every way, the Executive Committee met weekly and revised the Lifespan Respite work plan with assigned task leaders.
- The grantee shifted focus during the pandemic toward online promotion and training. Given that Montana is a large and rural state, it became obvious that developing online resources was essential – pandemic or not –, and that those new resources would contribute to program sustainability.
- The grantee initiated two new programs to support caregivers and recipients. The first distributed personal protective equipment, and the second distributed personal care items (robotic pets, weighted blankets, tablets, play materials and puzzles, for example) that provided respite by giving comfort, easing loneliness, or engaging care recipients.
Lifespan Respite Grantee Lead Agency: **Nevada – Aging and Disabilities Services Division (ADSD)**

**Funding Period:** September 1, 2017 to February 28, 2021

**Contact:** Jamie Ahumada at jahumada@adsd.nv.gov

**Primary Goal:** Strengthen and support services for family caregivers in Nevada through advocacy and capacity building.

### Key Performance Measures

The grantee collected data documenting: increases in the number of people served through public programs; increases in funding across the lifespan; and the percent of caregivers receiving respite services having more choice and control in their services. Products developed included: caregiver intake forms; respite enrollment applications; and respite pre- and post-surveys. In addition, an evaluation of the Respite Rx Project was conducted, and results were included in a report that was disseminated to stakeholders.

### Notable Achievements

The grantee completed a pilot project on self-directed caregiver respite, the Respite Rx Project, that incorporated best practices designed to translate to positive outcomes among caregivers receiving respite. The grantee’s goal was to remove internal and external barriers to respite services. The process of identifying these barriers led to continuous changes made to original policies to make them more relevant and supportive of caregivers using respite services.

### Objective 1. Coordinate respite services across state partners to expand capacity across the lifespan.

#### Notable Performance Outcomes

- During the grant period, ADSD saw the need for availability of one-time emergency funding to assist families during unplanned circumstances that result in an unavoidable absence of a primary caregiver, or occasions when primary caregivers needed other assistance.
  - An “emergency funds for caregivers” flyer was distributed statewide by respite partners Nevada Care Connection Resource Centers (Aging and Disability Resource Centers), ADSD community partners and staff, and other aging and disability professionals and were shared by word-of-mouth at various meetings with community partners.
  - ADSD assisted 34 caregivers with emergency funding assistance.

### Objective 2: Strengthen the Nevada Lifespan Respite Care Coalition to provide advocacy and education of respite in Nevada.

#### Notable Partnerships and Activities

- The Nevada Lifespan Respite Care Coalition, an advocate for respite services in Nevada’s No Wrong Door implementation, met monthly and worked to organize stakeholders, including competing providers, to create a strong voice for Nevada’s caregivers.
- The Nevada Aging and Disability Services Division, in partnership with the Nevada Lifespan Respite Care Coalition, worked to identify a sustainable structure and expand membership to

### Coalition, ADRC and Community Partners

**State and Community Partners**

Key partners in Nevada’s Lifespan Respite Project included the Nevada Lifespan Respite Care Coalition; the Department of Health and Human Services, Office of Community Partnerships and Grants; and the Division for Healthcare Financing and Policy (Nevada Medicaid); and Nevada Care Connection Resource Centers.

**State Respite Coalition/Organization Role**

The Nevada Lifespan Respite Care Coalition, a key advocacy partner for respite services in Nevada’s No Wrong Door implementation, worked to organize stakeholders, including competing providers, to create a strong voice for Nevada’s caregivers.
Key Objectives, Activities and Outcomes

- Support education and advocacy, expand the Coalition’s efforts to diversify membership and engage stakeholders, and enhance their involvement in the state’s lifespan respite program.
- In 2020, the Nevada Lifespan Respite Care Coalition held a two-day Virtual Respite Summit.
  - Topics presented by state and national respite leaders during the Summit included: *Current Status of Respite in Nevada; Respite Needs in the United States;* and *Innovative Respite Services for Families Caring for Children and Youth with Special Needs.*
  - Break-out sessions included strong representation from caregivers, occurred in tandem with presentations according to topic, and provided a forum for discussion and exchange of information and multiple perspectives.

Objective 3: Expand self-directed respite services to underserved populations including those in rural areas and adults with disabilities.

Notable Performance Outcomes

- The grantee conducted a pilot project on self-directed caregiver respite, the **Respite Rx Pilot Project**, that included a person-centered philosophy aimed at supporting caregivers; and filling gaps in the social service delivery system, specifically in rural areas.
  - During the pilot project period, 160 eligible families participated and received two to four hours of respite each week. Caregivers used on average 4.4 hours of respite per week.
  - Caregivers expressed their motivation for electing to use respite as: a desire for freedom (86%); social connections (71%); and need for support (56%).
  - Caregivers reported having a better perception of health; better relationship with their care recipient; and better relationships with others after having received respite services.
  - Caregivers rated their health status before receiving respite as good, very good, or excellent 67% of the time, and after having received respite, caregivers rated their health status as good, very good, or excellent 76% of the time.
  - Caregivers rated their relationship with the loved one they provided care for before receiving respite as good, very good, or excellent 85% of the time, and after receiving respite, they rated their relationship as good, very good, or excellent 94% of the time.
  - Caregivers reported high levels of commitment to care, signified by the desire to continue providing caregiving in their home, with 79.5% of respondents committed to caring for loved ones during their loved one’s lifetime.
- Nevada’s Division of Family Services (DFS) expressed interest in replicating a self-directed respite model for families of children with severe emotional disabilities. The grantee has been meeting with DFS to explore replication.

Program Flexibilities and Supports Introduced in Response to COVID-19

- The grantee used emergency respite funds to respond to COVID-19 related requests for respite.
- The Respite Rx pilot voucher program was not entirely affected during the pandemic. As a self-directed pilot program, the majority of caregivers used their own informal supports and felt comfortable continuing to do so.

Aging and Disability Resource Center Role

As part of implementation efforts, ADSD conducted refresher training for the Nevada Care Connection Resource Centers (ADRCs). As the designated entities to provide person-centered counseling and caregiver support services in Nevada, ADRCs are uniquely positioned to help caregivers identify the full range of respite and other caregiver support services available in Nevada.

For more information, contact ARCH at (703) 256-2084

archrespite.org
Lifespan Respite Grantee Lead Agency: New York State Office for the Aging (NYSOFA)

Funding Period: September 1, 2017 to August 31, 2021

Contact: Deana Prest at deana.prest@aging.ny.gov

Primary Goal: The overriding goal is to build upon prior and current Lifespan Respite Initiatives by engaging stakeholders to increase and expand access to respite services statewide, and enhance partnerships for education, outreach, and service provision to advance the development of the Lifespan Respite care system in New York State.

Key Performance Measures

During the grant period, an independent project evaluator incorporated five outcomes identified by the grantee into a logic model, and articulated complementary processes to structure and guide program evaluation and a subsequent report. New York State was particularly interested in identifying indicators to show the extent to which the respite program was successful in providing additional respite services through volunteers trained in the Respite Education and Support Tools (REST) model (described in Objective 2). In addition, New York measured increases in the number of REST Master Trainers statewide; increases in the number of REST Companion volunteers statewide; expansion of REST training in communities with limited English proficiency; satisfaction with training among volunteers participating in REST training; increased knowledge and awareness measured by survey following Caregiver Simulation training. Evaluation also included documentation of the establishment of NYS Lifespan Respite Resource Center; and production, process documentation, and dissemination of a final evaluation report and a Statewide Action Plan for Lifespan Respite Care for sustainability.

Notable Achievements

In 2019, the National Lifespan Respite Conference was hosted by ARCH and the New York State Caregiving and Respite Coalition (NYSCRC), and co-sponsored by NYSOFA. The Conference brought together more than 300 participants from public, non-profit, and private service providers across the country, as well as New York State local caregiver coordinators, respite providers, NY Connects staff, Expanded In-home Services for the Elderly Program case managers, and others involved in caregiving and respite across disciplines.

In 2018, New York State passed legislation requiring NYSOFA and the NYS Department of Labor (DOL) to develop a Caregiver Guide for Businesses to help support working caregivers across the state. A state-level workgroup was formed including NYSOFA, DOL, the NYS Worker’s Compensation Board (WCB), and the Department of Health (DOH) to develop The Caregiver Guide for Businesses. The guide, which was reviewed by key stakeholders, supports New York State’s business community and employed caregivers by providing relevant information on ways to best support working caregivers, including links to programs, supportive services, workplace data, and information about New York State Paid Family Leave.

Key Objectives, Activities and Outcomes

**Objective 1. Increase number of respite volunteers through additional training and recruitment activities.**

**Notable Performance Outcomes**

- To address gaps in the existing respite service delivery system, NYSCRC implemented the REST model for training respite volunteers, and implemented an online reporting portal to improve overall reporting, allowing the Core Team to closely monitor and report successes.
<table>
<thead>
<tr>
<th>Key Objectives, Activities and Outcomes</th>
<th>Coalition, ADRC and Community Partners</th>
</tr>
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<tbody>
<tr>
<td>NYSCRC added three master trainers, bringing the total to five master trainers in New York State.</td>
<td>State Caregiving and Respite Coalition (NYSCRC) have been working in partnership as the Lifespan Core Team since 2010, and continue to work with key stakeholders to build a statewide Lifespan Respite Program that is fully integrated into New York State’s LTSS system and is sustainable beyond the period of federal grant funding.</td>
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<tr>
<td>These master trainers trained an additional 89 trainers during the grant period, resulting in more Companion volunteers recruited, trained, and delivering respite.</td>
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<tr>
<td>New York State steadily increased its REST Companion volunteer pool by 32%.</td>
<td>State Respite Coalition/Organization Role</td>
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<tr>
<td>The number of Companion volunteers increased from 58 at the start of the grant in 2017 to 280 Companion volunteers in 2021, exceeding the targeted 30% increase in trained Companions.</td>
<td>NYSCRC has been working in partnership as part of the Lifespan Respite Core Team (The Core Team) since 2010 and continued to do so throughout the grant initiative. The Core Team also works with key stakeholders to build a statewide Lifespan Respite Program that is fully integrated into New York State’s LTSS system and is sustainable beyond the period of federal grant funding. In addition to sponsoring the National Lifespan Respite Conference in 2019, the NYSCRC sponsors annual statewide lifespan respite conferences. In 2020, NYSCRC presented a webinar series, providing an alternative learning and networking opportunity as a result of the pandemic.</td>
</tr>
<tr>
<td>Trained volunteers provided 16,144 hours of volunteer respite care during the grant project period.</td>
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<tr>
<td>In a large and populous state, New York has achieved 92% coverage, excepting only five of 62 counties.</td>
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<tr>
<td>When using an hourly rate of $25 for respite care in New York State, volunteer respite provision equated to a cost savings of approximately $403,601.</td>
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<tr>
<td>New York offered a Lifespan Respite Mini-Grant Program that funded eight state, local, and/or regional agencies serving caregivers of individuals across all age and disability spectrums. Applicants were required to use the REST model to develop or expand innovative local or regional community respite programs or services.</td>
<td>New York offered a Lifespan Respite Mini-Grant Program that funded eight state, local, and/or regional agencies serving caregivers of individuals across all age and disability spectrums.</td>
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<tr>
<td>Mini-Grant respite programs served 569 caregivers who received 8,870 hours of respite services.</td>
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<tr>
<td>Objective 2: Expand available respite services statewide through formalizing a caregiver-directed respite model.</td>
<td>Notable Performance Outcomes</td>
</tr>
<tr>
<td>To further address the shortage of available respite services, NYSOFA continued its efforts to formalize a caregiver-directed respite model under the National Family Caregiver Support Program (NFCS, Title III-E).</td>
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<tr>
<td>In 2018, NYSOFA issued a Program Instruction to the local Area Agencies on Aging (AAAs) advising that they may offer caregiver-directed in-home respite services funded under NFCS when providing respite services to benefit the caregiver.</td>
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<tr>
<td>Over the grant period, 19 AAAs were approved to offer caregiver-directed respite under the NFCS.</td>
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<tr>
<td>Objective 3: Expand access to caregiver services through improved respite listings in the NY Connects Resource Directory across age and disability types.</td>
<td>Notable Performance Outcomes</td>
</tr>
<tr>
<td>NYSOFA invests significant resources to develop and maintain the Statewide NY Connects Resource Directory, a statewide web-based platform at nyconnects.ny.gov aimed at improving public access to LTSS for individuals across all age and disability spectrums.</td>
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<tr>
<td>More than 21,000 providers and 75,000 programs listed in the Resource Directory offer provider information on a wide range of programs, services, and supports – including respite services – for individuals in need of LTSS and their caregivers.</td>
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<tr>
<td>Resources listed in the Directory are kept up-to-date by local NY Connects NWD staff, and through monthly data feeds containing LTSS providers and programs from NYS Department of Health (DOH), NYS Office for People with Developmental Disabilities (OPWDD), NYS</td>
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<tr>
<td>Key Objectives, Activities and Outcomes</td>
<td>Coalition, ADRC and Community Partners</td>
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<td>Office of Mental Health (OMH), and NYS Office of Alcoholism and Substance Abuse Services (OASAS), and food pantries across the state.</td>
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**Objective 4: Implement and continue to update the Statewide Action Plan for Lifespan Respite sustainability.**

**Notable Partnerships, Planning Activities, and Performance Outcomes**

- Two Lifespan Respite Sustainability Retreats were held in collaboration with NYSCRC, Lifespan of Greater Rochester, Inc., NYSOFA, and MCOFA and led by Dr. Thomas Caprio using a facilitated discussion with attendees serving as the core Sustainability Planning Workgroup.
  - The retreat objectives were: (1) examine the effort in coalition building through NYSCRC, including opportunities for membership expansion and enhanced engagement; (2) review sustainability self-assessment core elements and score the progress indicated in the self-assessment toolkit; (3) discuss performance measures to evaluate progress in planning and implementation; (4) develop action steps toward a statewide Sustainability Plan; and (5) identify potential challenges to sustainability.
  - Two products were produced from the retreats including the *Lifespan Respite Sustainability Logic Model* and the *Financing Strategies Logic Model*.

**Program Flexibilities and Supports Introduced in Response to COVID-19**

- All five (5) mini-grantees provided alternative respite care options to people receiving care, including virtual activities to provide respite to family caregivers.
- In place of its annual caregiver conference, NYSCRC presented six (6) webinar trainings on caregiving and respite for professionals, offering participants Continuing Education Unit (CEU) credits, as well as a webinar series focusing on “Diverse Elders.”

For more information, contact ARCH at (703) 256-2084

[archrespite.org](http://archrespite.org)
Lifespan Respite Grantee Lead Agency: Oklahoma Department of Human Services, Aging Services (OKDHS AS)

Funding Period: September 1, 2017 to August 31, 2021

Contact: Nadine Walter at Nadine.walter@okdhs.org

Primary Goal: Expand, enhance, and ensure the sustainability of gap-filling respite services to Oklahoma family caregivers across the lifespan and disability spectrum.

Key Performance Measures

Outcomes measured by the grantee included: the extent to which respite vouchers were easily accessible and manageable by caregivers; the success of the partnership with Oklahoma Aging and Disability Resource Consortium/No Wrong Door (OKADRC/NWD) in providing streamlined access to respite resources; increases in public/private partnerships; changes in caregiver health as a result of caregiver initiatives; and the number and type of policy development and events to promote caregiver services and ensure sustainability. Processes documented by the grantee included an on-line searchable database; the productivity of public/private partnerships; and employee caregiver training. Performance outcomes documented included increases in respite support; and pre- and post-respite surveys to determine the effectiveness of Oklahoma’s Lifespan Respite Grant Voucher Program.

Notable Achievements

The grantee regularly uses the Oklahoma Lifespan Respite Grant Caregiver Needs and Provider Survey to document characteristics of typical Oklahoma caregivers, care recipients, and service providers; services caregivers currently receive; services caregivers indicated they wished they had; and services that providers indicated that caregivers need. This resource, an excellent tool to help the Oklahoma Caregiver Coalition (OCC) partners identify and prioritize the needs of Oklahoma family caregivers, has shown that Oklahoma’s caregivers and providers identified respite as the number one need. Guided by documented service needs and priorities, Oklahoma’s Lifespan Respite Voucher Program provides typical, educational, and emergency vouchers to family caregivers across the lifespan through a creative and diverse service delivery approach.

Key Objectives, Activities and Outcomes

Objective 1. Advance existing lifespan respite services statewide.

Notable Partnerships, Advancement Activities, and Performance Outcomes

- An annual Oklahoma Caregiver Conference is held each November during National Family Caregiver Month at no charge to caregivers across the state.
  - Each year, approximately 250 family caregivers and 45 vendors with representation across the lifespan attend. All individuals on the program (emcee, keynote, breakout session speakers, and legislators) are or have been family caregivers.
  - Four legislators attended the Caregiver Conferences.
  - A Spanish interpreter provided translation for family caregivers.
  - After attending the conference, more than 95% of Caregiver Conference attendees felt more prepared to start or continue their caregiving role.

Coalition, ADRC and Community Partners

State and Community Partners

The Oklahoma Caregiver Coalition (OCC) provided the backbone to fulfill grant goals and objectives. Formed to improve the supports and experiences over the lifespan of caregivers through education, advocacy, and access to resources, the OCC included more than 170 public, private, and community partners. Various state partner agencies worked cooperatively and efficiently to develop supports for family caregivers and referred them to the program best suited to serve caregivers’ needs.
Key Objectives, Activities and Outcomes | Coalition, ADRC and Community Partners
--- | ---
• Statewide respite program staff (AARP Oklahoma, SS, VA, DDS, AAA, Foster Care, adult day programs) were invited by various conference/workshop planners, businesses, faith-based organizations, etc. to present information to current or future caregivers to gain knowledge regarding respite services in Oklahoma through Lunch and Learns/Workshops. A panel of speakers provide an abundance of well-produced resources to assist the various needs of caregivers and tools to access respite.
  ▪ These events also generated additional OCC partners, and increased understanding of respite services.
• To address the complex maze of federal, state, local and private service systems grandparents and other relatives raising children frequently encounter, the grantee connected with a representative of Oklahoma’s GrandVoices Racial Equity Initiative, which is supported by Generations United. The Initiative’s purpose is to improve culturally appropriate supports and services to African and Native American grand families by elevating their voices, perspectives, and expertise to inform and influence policy, practice, and research.
  ▪ Native and African American grandparents raising children gathered at a roundtable event to voice challenges they face in fulfilling their unexpected parenting role.
  ▪ A report on the roundtable summarized key findings, including the need for a Caregiver Resource Center to provide essential supports to keep families together, assist in children’s overall wellbeing, and avoid foster care or costly institutionalization.

Objective 2: Actively collaborate with the Oklahoma Caregiver Coalition (OCC).

Notable Partnerships and Collaborative Activities
• On the Road trainings brought caregiving providers (many were OCC partners) together to share resources and services with caregivers and care recipients in strategically placed locations across the state, connecting local resources and caregivers, and bringing providers together to network.
  ▪ Caregivers reported that the best thing about the trainings was that they learned the names and contact information of individuals that could assist them in accessing resources in their communities.

Objective 3: Develop policies and strategies to sustain access to respite services.

Notable Policy and Sustainability Activities
• The OCC Executive Committee and Respite Subcommittee partners participated in a strategic planning process, referencing ARCH’s Sustainability Planning Workbook, to expand and sustain respite services in Oklahoma.
  ▪ One outcome from strategic planning was securing a non-profit entity, WovenLife, as the OCC’s fiscal and administrative sponsor — a natural fit as fiscal sponsor for the OCC since they have served as the fiscal agent for the 2013 and 2017 LRGVP.
  ▪ WovenLife was also instrumental in managing the fiscal needs of the Oklahoma Caregiver Conference and assisting the OCC in accepting donations to support respite services.
• An Oklahoma State Representative requested an interim study to examine physical and mental health implications and financial costs to unpaid family caregivers.
  ▪ The study examined what kinds of help family caregivers needed, and what was currently available to help family caregivers.
  ▪ Family caregivers, including those with children or parents with special needs, and grandparents raising grandchildren, shared information about their day-to-day caregiving challenges.

State Respite Coalition/Organization Role
Oklahoma Caregiver Coalition (OCC) meetings provide an opportunity for more than 170 partners to attend quarterly meetings and discuss pressing issues affecting caregivers. Every partner was asked to serve on one of nine subcommittees, creating a forum for partners to individually and collectively share their wealth of knowledge, and encouraging individuals and organizations to share caregiver resources like never before.

Aging and Disability Resource Center Role
Oklahoma ADRC/No Wrong Door were key and formal partners in providing streamlined access to respite resources. This strong partnership is identified as a key outcome in Oklahoma’s Lifespan Respite Grant.
Caregivers reported that their number one need was respite, and they conveyed the benefits of respite and the savings associated with prevention of costly institutionalization.

Objective 4: Evaluate and disseminate program results.

Performance Outcomes
- All grant activities, and additional activities performed as part of the lifespan respite grant, were evaluated according to a written plan with expected outcomes and indicators. Data were collected throughout the funding period through forms and surveys, or documentation of processes. Evaluation results were made available in multiple user-friendly formats.
  - 634 caregivers received Lifespan Respite Grant (LRG) vouchers.
  - Of those using vouchers, 88% of those believed they would not receive respite if the LRG Voucher (LRGV) program was not available.
  - Of those using vouchers, 95% of caregivers used the full voucher amount for respite.
  - 97% of caregivers rated their satisfaction with the LRGV program “extremely” or “very” satisfied.
  - 93% of caregivers reported lower levels of stress following the use of LRGV respite services.

Program Flexibilities and Supports Introduced in Response to COVID-19
- The grantee introduced new flexibilities in the respite voucher program, including increased respite voucher amount; expanded provider eligibility to include someone who lives with the caregiver and care recipient; and lifting of the household income requirement.
- The grantee made Caregiver Care Bags including blankets, water bottles, hand sanitizer, face masks, healthy snacks, adult coloring books available through a socially isolated drive-through pick up station.
**Lifespan Respite Care Program**

**Lifespan Respite Grantee Lead Agency:**  
**State of Rhode Island Office of Healthy Aging**

**Funding Period:**  
September 1, 2017 to August 31, 2021

**Contact:**  
Aleatha Dickerson at Aleatha.Dickerson@oha.ri.gov

**Primary Goal:**  
Integrate, bring to scale, and achieve long-term sustainability of Lifespan Respite Services in the State.

### Key Performance Measures

In addition to evaluating the quality of student training and individual student learning, the grantee measured the number of nursing students providing respite; the duration of their service; and collected an unduplicated number of families served throughout the grant period. Caregiver characteristics, resources, individual goals, and outcomes were measured for each participating family, and family satisfaction with respite services was measured throughout, as were students’ individual evaluations of their training and clinical experiences providing respite.

### Notable Achievements

A promotional video incorporating testimonials from nursing school grant partners, student participants, and caregivers conveying the importance and benefits of the volunteer nursing student respite initiative was produced and disseminated by the grantee, working in partnership with Healthcentric Advisors. A powerful tool demonstrating the meaning of respite and its worth to providers, families, and communities, the video has reached local, state and national audiences through two targeted marketing plans.

### Key Objectives, Activities and Outcomes

**Objective 1. Expand the Rhode Island student nursing workforce development initiative.**

**Notable Performance Outcomes, Partnership Activities and Products**

- The grantee established two new programs – at Rhode Island College and the University of Rhode Island – as they continued previously established programs.

- A clinical placement option for nursing students was established at Salve Regina University and the New England Institute of Technology.
  - New clinical placement options matched students with low to moderate income families lacking access to subsidized respite care.

- During the project period, in the nursing training programs combined:
  - 191 students provided respite to more than 60 families.
  - Caregivers reported experiencing relief from emotional stress, and increased time with family and friends, household routines, chores, and errands as a result of having used respite services.

- The University of Rhode Island held eight group respite events for pediatric care recipients in 2021 with 26 students and more than 30 children participating.

### Coalition, ADRC and Community Partners

**State and Community Partners**

Key partners include Caregiver Alliance of Rhode Island, United Way of Rhode Island, Catholic Social Services of Rhode Island, Rhode Island College, University of Rhode Island, New England Institute of Technology, and Salve Regina University.

**State Respite Coalition/Organization Role**

In an ongoing collaboration with the Caregivers Alliance of Rhode Island, the grantee held regular meetings of the Family Caregiver Alliance of RI Advisory Committee; launched and updated the Family Caregiver Alliance of RI website; and planned and held annual Family Caregivers Conferences.
Key Objectives, Activities and Outcomes

- Catholic Social Services of Rhode Island assisted caregivers and families by providing a cost-share of Lifespan Respite funding for respite care provided by home care agencies, adult day centers, assisted living facilities and nursing homes under their CareBreaks respite program.
  - During the project period, 241 unduplicated caregivers and their families received respite, exceeding the anticipated target of 195 families.
- In partnership with the University of Rhode Island, Rhode Island College, Salve Regina University and New England Institute of Technology, the grantee created, tested, revised, and disseminated a Nursing Student Respite Training Toolkit to assist nursing programs throughout the nation interested in replicating a volunteer respite program.

Objective 2: Enhance the framework of the state’s respite program through the Family Caregivers Alliance of Rhode Island.

Notable Partnerships and Development Products and Activities
- The lifespan respite framework was strengthened during the grant period by the development of the first Rhode Island State Plan for Family Caregivers.
  - The Plan identifies specific goals, objectives, and action steps to expand support for family caregivers, and it provides a framework for developing and expanding efforts to support caregivers through policies, programs, and partnerships going forward.
- In an ongoing collaboration with the Caregivers Alliance of Rhode Island, the grantee held regular meetings of the Family Caregiver Alliance of RI Advisory Committee; launched and updated the Family Caregiver Alliance of RI website; and planned and held annual Family Caregivers Conferences.

Objective 3: Improve awareness about and access to respite services.

Notable Access and Awareness Promotion Activities
- Rhode Island’s access and awareness activities reached multiple audiences across the state.
- Rhode Island’s Aging and Disability Resource Center provided information at more than 1,000 outreach events in community settings throughout the state during the grant period. During these events, caregivers received assistance and caregiver information and resource booklets from staff trained specifically to share this information and support caregivers.
- Rhode Island’s lifespan respite project hosted the first Rhode Island caregivers conference, supported by 10 vendors, with attendance nearing 100.
- The grantee reached more than 500 medical providers including physicians, nurses, dieticians, pharmacists, certified nursing assistants, licensed practical nurses, and support staff at nursing homes, assisted living facilities, adult day centers, and other community organizations over the project period to increase awareness about respite and increase the number of referrals of caregivers for respite support services.
- Healthcentric Advisors reached more than 700 professionals in the medical community during the funding period, increasing awareness of respite, and increasing the likelihood that medical personnel will refer families to respite programs in the future.
- During the funding period, the Point (Rhode Island’s ADRC) trained 129 staff on available respite services.

Program Flexibilities and Supports Introduced in Response to COVID-19
- Catholic Social Services CareBreaks respite program funded by Lifespan Respite grant funds undertook rapid processing of program applications which enabled home care agencies to continue providing services to clients during the pandemic.

Aging and Disability Resource Center Role
The Rhode Island Aging and Disability Resource Center (ADRC), known as the “Point,” has been a partner in the Lifespan Respite project since its inception. The Point, operated by the United Way of Rhode Island (UWRI), serves as an accessible walk-in and call-in portal for the ADRC. In addition, throughout project funding, the ADRC provided information at more than 1,000 outreach events in community settings.
Key Objectives, Activities and Outcomes

- Catholic Social Services staff contacted every participating client in the volunteer nursing student initiative to offer other CareBreaks services when the student initiative was put on hold.

- Although the COVID-19 pandemic interrupted volunteer nursing student respite services, three (3) of the four (4) nursing programs were able to utilize creative approaches to bring back some type of respite services during the fall 2020 or spring 2021 semesters, including in-home respite.

For more information, contact ARCH at (703) 256-2084
Lifespan Respite Grantee Lead Agency: **South Carolina Department on Aging (SCDOA)**

**Funding Period:** September 1, 2017 to August 31, 2021

**Contact:** Josh Houben at [JHouben@aging.sc.gov](mailto:JHouben@aging.sc.gov)

**Primary Goal:** Develop new public and private partnerships that further expand and strengthen SC’s coordinated lifespan respite system engaging a broader cross-section of stakeholders for future sustainability.

### Key Performance Measures

To measure the impact of this Lifespan Respite Project, the grantee utilized both quantitative and qualitative sources including: documentation from all project activities; surveys of the State Committee on Respite; surveys of caregivers; and focus groups with Respite Breakroom leaders. A formal evaluation plan identified measurable indicators for each objective and sources of funding that supported, and/or will continue to support objective-associated activities.

### Notable Achievements

At the end of Year 1 funding, SCDOA received a supplemental award that allowed them, in partnership with the South Carolina Respite Coalition (SCRC), to expand their work with faith communities and to develop the Respite Breakroom model. This model encourages faith communities to provide respite to family caregivers during religious services and/or organized events through supervision, socialization, and care for loved ones while caregivers participate in congregational activities.

### Key Objectives, Activities and Outcomes

**Objective 1.** Expand and strengthen the involvement of key state and local public and private stakeholders from across the age and disability spectrum as full partners in the continued design, implementation, and evaluation to further develop and sustain SC’s coordinated lifespan respite system (*State Plan Recommendation 1*).

#### Notable Partnerships and Sustainability Activities

- South Carolina’s Coordinated Lifespan Respite Program brings together Federal and State funding to create more seamless access to respite, particularly respite voucher resources.
  - The state-funded State Voucher Program, initially established in SFY2014 as part of the SC Department on Aging budget, stabilized in SFY2018 at an annually recurring amount of $2.4 million.
  - Coordination of voucher distribution continued to improve during the grant period with common data being entered and tracked in the SC Department on Aging’s AIM and QuickBase databases.
- The State Committee on Respite (SCOR) and primary partners met quarterly to implement the recommendations in the Lifespan Respite State Plan.
  - A third Regional Advisory Council was established in the PeeDee region providing local representation to three quarters of the state.

### Coalition, ADRC and Community Partners

**State and Community Partners**

A major strength of the SC Lifespan Respite Program is that its foundation is built on solid and long-term relationships among its three primary partners: SC Department on Aging, SC Respite Coalition (SCRC) and Family Connection of SC (Family Connection). The experience and expertise of these partners combine to ensure that the needs and perspectives for all family caregivers across the lifespan are addressed. Through monthly meetings, primary partners met to plan strategies and coordinate activities to implement goals and objectives as well as identify challenges and modifications needed.
All Regional Councils met quarterly, as well.

Substantial progress made during the grant period was largely due to the collaborative feedback process that allowed for adjustments, as needed, based on lessons learned along the way.

There was increased coordination across respite information resources that started in previous grants and improved significantly with the development of the SCDOA’s GetCareSC website and the new SCRC website.

**Objective 2: Integrate a respite/caregiver focus to change systems by providing tools to increase awareness and understanding of the need and benefits of respite by caregivers, health care and human service personnel, community members, faith community, and business leaders in order to identify family caregivers and connect to respite services (State Plan Recommendations 2, 3, 4).**

**Notable Respite Integration Activities**

- Because even professional organization leaders do not always understand how respite might be a need of their constituents, the SC Department on Aging and SCRC tackled this challenge through the following activities:
  - The grantee made presentations at related conferences, spoke to professional groups, and regularly participated in a diverse group of meetings of health and long-term care professionals.
  - The grantee directed outreach and sent materials to primary care practitioners emphasizing their role in identifying family caregivers in their practice, educating them about respite, and referring caregivers for respite.

**Objective 3: Expand promising practices to increase awareness, develop respite services, and to recruit and train respite providers, paid and unpaid, in faith communities (State Plan Recommendation 5).**

**Notable Expansion Activities**

- The grantee developed a Respite Breakroom model for faith communities.
  - Six Respite Breakrooms were established during the project period, four that opened before closure due to COVID, and two that are preparing to open once church is back to full operations.

**Objective 4: Fill gaps and increase availability of respite providing vouchers across the lifespan and using lessons learned to inform policy development and strategies to sustain and increase access to respite services beyond the life of the grant.**

**Notable Performance Outcomes**

- A coordinated respite voucher system worked to address gaps in respite services, and a growing number of family caregivers across the lifespan received respite vouchers during the project period.
  - In SFY2018, 410 caregivers received 12,787 hours of respite through SCRC Lifespan respite vouchers.
  - The number of caregivers served increased to 575 families receiving 20,637 hours of respite in SFY2020.
- Through attention to long-term and diverse funding, the sustainability of the South Carolina Lifespan Respite System was strengthened by the grantee and partners.

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**State Respite Coalition/Organization Role**

The South Carolina State Respite Coalition is a key partner in working on sustainability and developing a long-term State Respite Plan.

**Aging and Disability Resource Center Role**

ADRCs are partners in the state’s Coordinated Lifespan Respite System. The Family Caregiver Support Program, State Voucher Program and state funded Alzheimer’s respite funds are all administered through the AAA/ADRC Family Caregiver Advocates, with SCRC managing Lifespan grant vouchers and State vouchers to younger and mid-life families or those without other respite sources.
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<tr>
<td>▪ The grantee maintained the $2.4 million recurring state dollars in the Department on Aging budget specifically for lifespan respite.</td>
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<tr>
<td>▪ The grantee maintained the $900,000 in state legislative appropriations through SCDMH to SCDOA for respite care for caregivers of persons with Alzheimer’s, avoiding a shortfall of $128,000.</td>
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<td>▪ The grantee maintained funding for eight non-emergency overnight respite beds (two at each of four DDSN residential facilities).</td>
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<tr>
<td>▪ SCRC received a grant from SC Physicians Care Charity for $50,000 to support respite vouchers for family caregivers.</td>
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<td>▪ SC Medicaid (SCDHHS) and SCDDSN changed state respite policy to increase the reimbursement rate for respite from $12.40/hour to $16.24/hour which will make a significant difference in recruitment of individual respite providers and in workforce development.</td>
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**Program Flexibilities and Supports Introduced in Response to COVID-19**

- SCRC adapted to pandemic closures by employing virtual meetings with stakeholder groups, virtual webinars and respite events, Caregiver Open Houses for support, graphics and technological alternatives for videos, virtual trainings for Breakrooms, and a series of webinars in lieu of the Faith Conference.

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For more information, contact ARCH at (703) 256-2084

[archrespite.org](http://archrespite.org)
Lifespan Respite Grantee Lead Agency: **Tennessee Commission on Aging and Disability (TCAD)**

**Funding Period:** September 1, 2017 to August 31, 2020

**Contacts:** Ondria Stevenson at Ondria.M.Stevenson@tn.gov

**Primary Goal:** Respond to the needs determined by the community conversations held under the current Lifespan Respite Care Act funding.

### Key Performance Measures

The grantee identified quantitative, qualitative, product, and event outcomes to demonstrate the merit of their work including:

- The development and delivery of respite provider training to include 150 newly trained providers.
- An approximate 20 percent increase in calls to the State Respite Helpline over baseline.
- Reduction in stress and desire to utilize respite again reported by 80 percent of family caregivers.

The grantee also developed a business plan; and convened at least four meetings with potential funders for respite vouchers.

### Notable Achievements

To meet the challenge of providing respite services during the pandemic, the Tennessee Respite Coalition (TRC) conducted a client survey to determine what caregivers needed to feel supported. Based on survey results, the TRC developed an innovative caregiver support program that expanded upon traditional respite services, including the purchase of Caregiver Tablets to enable caregivers to access online support and discussion groups; PPE to help caregivers to safely provide care; and electronic care packages that contained self-care activities, resources, and caregiver playlists, delivered to 97 family caregivers in Tennessee.

### Key Objectives, Activities and Outcomes

**Objective 1. Establish a standard training curriculum for respite providers in Tennessee.**

**Notable Planning Activities**

- The TRC discussed possibilities for using technology for respite provider training and caregiver support tools, worked to hire an intern dedicated to the project, and revised a plan so that the training website would be combined with the TRC website.

**Objective 2: Create a seamless system for family caregivers to access trained providers.**

**Notable Performance Outcomes, Partnerships and Activities**

- The TRC worked to widely promote the availability of the Statewide Respite Helpline and Respite Voucher Program, with the assistance of TCAD and other state agencies, and public and private sectors.
  - The Statewide Respite Hotline received 3,897 calls from family caregivers.
  - The TRC partnered with the virtual reality center at Tennessee Technological University, and created innovative resources for caregivers accessible via website, including: a caregiver

### Coalition, ADRC and Community Partners

**State and Community Partners**

In addition to a close partnership with the Tennessee State Respite Coalition and Aging and Disability Resource Centers, the grantee formed a partnership with Tennessee Tech University to explore the use of technology for respite provider training and caregiver support tools.

**State Respite Coalition/Organization Role**

The Tennessee Respite Coalition (TRC) is the Tennessee Commission on Aging and Disability’s key partner in meeting the objectives of this lifespan respite project.
stress questionnaire, E-learning modules, a 360-degree visual experience for caregivers, and a guide to hiring qualified respite providers.

**Objective 3: Promote current respite services to caregivers and the general public.**

**Notable Performance Outcomes**
- TRC staff presented and/or distributed information across the state to educate caregivers, professionals, and the general public about respite.
  - During the funding period, respite promotion information reached attendees at 46 different events.
- TRC periodically disseminated newsletters that contained information related to respite services, the importance of self-care, community resources, and a Caregiver Appreciation Event.
- TRC used social media, including Facebook Life events focusing on caregiver self-care to reach caregivers and the general public.
- TRC partnered with the Council on Aging of Middle Tennessee to implement an environmental assessment to understand what employers know about their employees and caregiving responsibilities.

**Objective 4: Increase the availability of respite vouchers for all caregivers.**

**Notable Performance Outcomes**
- Voucher use during the funding period reached caregivers across Tennessee.
  - Tennessee’s statewide respite voucher program served 853 caregivers and provided 44,392 hours of respite.
  - Of those caregivers, 94% of caregivers responding to the survey reported experiencing a reduction in stress and 54% reported a desire to use respite services again.

**Program Flexibilities and Supports Introduced in Response to COVID-19**
- TRC conducted a client survey to determine what caregivers needed to feel supported during the pandemic.
- TRC purchased Caregiver Tablets to enable caregivers to access online support and discussion groups; PPE to help caregivers to safely provide care; and electronic care packages that contained self-care activities, resources, and caregiver playlists, delivered to 97 family caregivers in Tennessee.

**Aging and Disability Resource Center Role**
The grantee worked collaboratively with AAAD/ADRCs to carry out the stated goals and objectives of the grant project. The AAAD/ADRCs independently evaluate caregiver satisfaction via surveys. The Tennessee State Plan on Aging (2017-2020) includes strategies for TRC to partner with AAAD/ADRCs to ensure that caregivers’ needs are addressed through respite and other long-term supports and services.
**Lifespan Respite Care Program**

**Lifespan Respite Grantee Lead Agency:** Washington Aging and Long-Term Support Administration

**Funding Period:** September 1, 2017 to August 30, 2022

**Contacts:** Dana Allard-Webb at dana.allardwebb@dshs.wa.gov

**Primary Goal:** Increased accessibility to respite for underserved populations, including caregivers of persons living with a Traumatic Brain Injury or Developmental Disability, caregivers from American Indian/Alaskan Native communities, and caregivers from rural areas.

### Key Performance Measures

The grantee collects process and performance data on the number of respite provider applications, application processing time, and eligibility; tracks and monitors registered providers on the website, Salesforce System; documents the number of website visitors and how they use the website; and evaluates the alignment of caregiver needs and respite system responses. The grantee documents and tracks dissemination of products and communications including: surveys developed and administered; application development and revision; presentations; flyers, newsletters, postcards, and booklets. The grantee refined the online voucher application and reporting processes, yielding concrete, trackable monthly data in multiple categories: number of awards by state regions; amount of funding expended in each category; and number of vouchers expiring by month. These refinements improved month-to-month comparisons while streamlining useable data and expanding available information.

### Notable Achievements

During the funding period, six tribal members belonging to the Port Gamble S’Klallum Tribe completed a Washington Training Partnership-approved online training to become home care agency direct care workers qualified to work as respite workers for tribal members. This important milestone established a foundation for trust and connections between family caregivers and tribal community members who understand customs and know their community members, helping to promote feelings of safety and comfort among caregivers and families. A tribal home care agency provides oversight for quality assurance. The grantee is working to develop a training specifically for tribal communities, and plans to use it as a template for other tribal respite direct care worker training.

### Key Objectives, Activities and Outcomes

**Objective 1. Ensure equitable voucher distribution across the state.**

**Notable Partners, Activities, and Performance Outcomes**

- In a state where one western county has a higher population than the entire eastern half of the state, one objective of Washington’s Lifespan Respite grant was to ensure equitable voucher distribution across the state. PAVE worked to increase respite access and services in all regions the state.

- The grantee tracked vouchers awarded to eastern and western locations in the state to ensure equitable voucher availability, and collected data on self-disclosed ethnicity and race to monitor equity among populations served.

### Coalition, ADRC and Community Partners

**State and Community Partners**

Key partner for Washington’s Lifespan Respite grant, Partnership for Action, Voices for Empowerment (PAVE), worked tirelessly to increase respite access and services in Washington.

The grantee met with the Developmental Disability Council and the Developmental Disability Administration (DDA) to begin a
Objective 2: Provide outreach to underserved populations across the state.

Notable Partners and Expansion Activities

- Lifespan Respite Washington (LRW) participated in twice yearly tribal summits.
- During year three of the grant, the grantee contracted with Port Gamble S’Klallam tribe to offer training to tribal members wanting to provide respite for a family member or friend.
- The grantee made a no-cost training available for paid and unpaid caregivers of people with traumatic brain injury, helping to ensure that respite providers understand the specific needs of people with a brain injury.
- A no-cost monthly support group for unpaid family caregivers was established and is hosted by the Traumatic Brain Injury Council.

Objective 3: Increase Respite Options.

Notable Partnerships, Activities, and Performance Measures

- The grantee built and tested Salesforce System – a HIPPA-compliant, robust, outcome-driven Lifespan Respite Washington data system.
  - The grantee hired staff, recruited respite providers, updated the website, made both Caregiver Respite Applications and Respite Provider Applications online, and entered hundreds of prior unfunded voucher applications into the new system.
  - August 31, 2020, the grantee registered 54 respite providers in all 35 counties.
  - August 31, 2021, the grantee registered 72 respite providers in all 35 counties.
  - March 31, 2022, the grantee registered 126 respite providers in all 35 counties.
  - June 1st, 2023, the grantee registered 81 respite providers in all 35 counties.

Program Flexibilities and Supports Introduced in Response to Covid-19

- Lifespan Respite Washington (LRW) not only continued providing respite services during the pandemic, they used the crisis as an opportunity to create flexible options for family caregivers.
  - LRW reached out to family caregivers by email to see how they were doing, address immediate concerns, and extend their voucher usage time frame. LRW later held in-depth phone calls with family caregivers to follow-up on voucher awards, and to discuss and conduct respite options searches.
  - In addition to increased flexibility in voucher scheduling, LRW expanded respite options that allowed caregivers to use vouchers for settings outside the family home, including YMCAs, 4H Clubs, and horseback riding/equine classes. LRW also initiated collaboration among providers to explore using camp facilities for non-traditional respite opportunities, such as weekend get-a-ways, retreats, or tutoring to support work and education.

For more information, contact ARCH at (703) 256-2084