



State Summaries of Lifespan Respite Grant Activities and Outcomes

*Final Reports
FY 2020 Grantees*





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Summaries from some FY 2020 state grantees were not included in this report because they were granted no-cost extensions and their final reports will be summarized when their grants have concluded.



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 2020 State Lifespan Respite grantees that chronicle grant activities from FY 2020 through FY 2023-24, the projects' outcomes, accomplishments, and successful partnerships are highlighted. Especially noteworthy are the flexibilities grantees have maintained in respite voucher programs, mini-grants, and volunteer efforts that were introduced during the COVID-19 pandemic, and the creative respite, mental health supports, and education alternatives that are still used to ensure that caregivers are 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 with out 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.



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Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Alabama Department of Senior Services (ADSS)**

Funding Period: September 1, 2020 – August 31, 2023

Contact: Roxanne Diawara at roxanne.diawara@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 that will expand and strengthen Alabama’s current lifespan respite care initiatives.**

Key Performance Measures	Notable Achievements
<p>During the grant cycle, more than 2,700 unduplicated families received more than 140,000 respite hours, including training, universal respite, and emergency respite. Caregivers provided feedback via online surveys about why respite was important to them. Survey results showed that families served were very pleased with workshops across the state. Data collected from voucher recipients showed that using respite services improved caregivers’ mental, physical, and spiritual health, and allowed them to relieve some stress and focus on their own well-being. To measure project impact, staff collected quantitative and qualitative data including: a formal internal evaluation; surveys of caregivers; and numerical performance and outcome measures. This information supports legislative efforts to increase funding; increase new and enhance existing support services; and advance Alabama’s coordinated systems of respite options.</p>	<p>During the 2022 Legislative Session, Alabama Respite advocated for and received a \$140,000 increase to the annual Education Trust Fund (ETF) state appropriation via the Alabama Department of Rehabilitative Services as a match for potential increased, new, or rollover federal funding opportunities. Increased funds, as well as increased legislative awareness and bi-partisan support, helped the grantee reach all project goals and objectives to support caregivers statewide. In addition, during the final year of the project, funding was made available to partner with Alabama Lifespan Respite (ALR) as the first non-state agency to be included in the ADSS/ADRC/AAA PeerPlace referral portal as a pilot project. Technical assistance was offered through ALR, Coalition, and the Caregiver Wellness Initiative (CWI), and 10 mini-grants were awarded for startup or expansion of community respite programs.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1. Reach underserved populations, including caregivers in rural areas, to increase new and existing support services.</p> <p>Notable Products and Performance Outcomes</p> <ul style="list-style-type: none"> • ALR launched the new Caregiver Wellness Initiative (CWI) to increase emergency respite funds and make available mental health counseling stipends to caregivers enrolled in any ALR reimbursement program. <ul style="list-style-type: none"> ▪ Staff contracted with five licensed mental health providers across the state to provide crisis counseling, often using various telehealth platforms. ▪ Staff acquired and delivered Wi-Fi-enabled tablets that helped facilitate counseling via tele practice. 	<p>State and Community Partners</p> <p>Alabama Lifespan Respite (ALR) staff consistently engage in providing technical assistance to advance the Caregiver Wellness Initiative (CWI) as a means of promoting respite options and collaborating with other programs to improve the quality and availability of support services and respite.</p> <ul style="list-style-type: none"> • One collaboration included technical assistance with the Alabama Head Injury Foundation and focused on lessons

- To begin, 31 caregivers from 18 counties applied for counseling stipends, and 275 caregivers from 39 counties received caregiver wellness counseling stipends during the funding period.
- An additional private grant fund through Venturi Brighter Day was awarded, further increasing this new caregiver support service initiative.

Objective 2: Increase collaborations with state and local agencies and public-private partnerships to increase respite and respite education.

Notable Expansion Activities and Performance Outcomes

- Upon review, Alabama’s well-established “No Wrong Door” (NWD) referral process for family caregiver services and supports was found to be difficult and time-consuming. Therefore, ADSS reevaluated current practices with the goal of removing difficult steps in and simplifying the referral process for family caregivers who call in during a crisis.
 - In their proactive effort, ADSS collaborated with the Aging and Disability Resource Center (ADRC) and suggested that ALR be allowed access the AAA PeerPlace system and retrieve referrals in a way that would provide high performance and maintain person-centered principles.
 - In May, 2023, ADSS worked with the West Alabama Regional Planning Commission (WARC) to initiate all ADRC referrals for the ALR program directly through the PeerPlace data management system, offering a single-point-of-entry system designed to link call center information and assistance specialists with long-term services and supports (LTSS) resources.
 - The PeerPlace interface allowed I&R specialists to track, enter data, refer, and manage multiple information requests at one time while seamlessly communicating with family caregivers.
 - Twelve of thirteen AAA PeerPlace users sent referrals directly to ALR — their first time connecting with organizations outside of the network to the PeerPlace Platform.

Objective 3: Advance coordinated systems of respite options to improve the delivery, quality, and availability of respite services for all caregivers.

Notable Partnerships and Performance Activities

- Recognizing significant service gaps for caregivers of family members with mental illness or intellectual disabilities, Alzheimer’s, or other cognitive disorders, autism spectrum disorders, returning wounded soldiers, and those with stroke or brain injury, Coalition members worked to increase the involvement of small non-profit and faith-based organizations in serving these frequently overlooked populations.
 - ALR staff participated in and presented successful respite models for replication. One presentation, “Achieving Respite Through Mental Health Supports,” highlighted ALR’s Caregiver Wellness Initiative (CWI) and provided information for replication of caregiver mental health counseling, supports in other respite programs, and the provision of stipends to help sustain caregivers’ health as they fulfilled their role in caring for loved ones.

learned and best practices for its caregiver mental health program.

- Senior and Family Matters, Inc. of Trussville, Alabama sought assistance from ALR regarding a new emergency respite program for senior caregivers.
- The CORE Project, Inc. received an ALR mini-grant to provide a summer respite program for individuals living with severe autism. Seventy-nine family caregivers of twenty-four individuals from eight to 25 years-of-age received summer respite.

State Respite Coalition/ Organization Role

Alabama Lifespan Respite (ALR) is based on strong, long-lasting partnerships with public, private, and coalition sectors. The Alabama Respite Coalition members are key partners in working toward increased respite, respite education, and continued sustainability. To ensure that the needs and perspectives of all family members across the lifespan are addressed, their combined experience and knowledge are used. Members of the coalition met every three months to coordinate efforts toward achieving goals and objectives, to talk about strategies, and to identify issues and potential solutions. During meetings, the ALR voucher system and any barriers were carefully examined to guide decisions about future policies and practices.

Aging and Disability Resource Center Role

In addition to the partnership and activities described under Objective 2, the ALR further strengthened collaborations with the local Area Agencies on Aging (AAA) partnerships by receiving robotic pets and distributing them to aging caregivers served by ALR statewide.

Program Flexibilities and Supports Offered in Response to Ongoing COVID-19 Pandemic

- ALR supported caregivers during the holiday season by creating and sharing the “Holiday Health & Safety Items Assistance” as well as the “12 Days of Care Giving” campaign.
- ALR awarded assistance to 100 caregivers enrolled in the Universal Respite Reimbursement program, allowing caregivers to purchase specific items such as hand sanitizer, masks, and cleaning products.
- To address caregivers at financial risk and to reduce caregiver stress and anxiety brought on by the pandemic, ALR provided gift cards for purchasing groceries, prepared meals, health, and hygiene items to safely provide care, gas, etc.



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

Lifespan Respite Care Program



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

Funding Period: September 1, 2020 – February 29, 2024

Contact: Lynn Fyanes at lynn.fyanes@aging.idaho.gov

Primary Goal: **Establish a lifespan respite program that expands, enhances, and improves access to respite services throughout the state for family caregivers of people of all ages.**

Key Performance Measures	Notable Achievements
<p>Grantee partner Boise State University – Center for the Study of Aging (BSU-CSA) conducted an analysis of consumer-directed respite (CDR) programs using a retrospective pre-test survey administered by the Area Agencies on Aging (AAAs) from March 1, 2021 through February 2023. Results of the survey from 124 participants indicated significant positive outcomes in caregivers’ perceived ability to find and pay for respite; cope with stress; care for their loved one at home; and address other challenges frequently associated with caregiving. Evaluation measures showed statistically significant positive changes on all factors. Other measurable outcomes showed an increase in available respite services and heightened awareness among caregivers about respite resources. Participants providing qualitative comments indicated a need for more qualified respite providers with training in toileting, lifting, working with children, and communication and listening skills.</p>	<p>The grantee’s key accomplishments included: 1) the development of Idaho’s management information system infrastructure to accommodate AAAs CDR and State Program Report (SPR) accountability; 2) Idaho’s HB 687, the appropriation bill for the Commission on Aging that included \$720,00 in ongoing funding to improve access to care for vulnerable seniors and direct support for their caregivers; 3) three annual ICA Caregiver Conferences and a Lifespan Summit; 4) the development of ICAs website, resource library, monthly newsletters, Idaho legislative updates; 5) increased outreach and awareness; 6) the foundation and expansion for AAAs to implement the CDR model in providing homemaker and transportation services in rural communities; 7) cross-sharing of state’s Medicaid Money Follows the Person Program, Family Caregiver Navigator to help inform changes in the caregiver support system statewide; and 8) consumer evaluations.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1. Implement a state consumer-directed lifespan respite (CDR) program designed for caregivers who do not have access to respite through other means.</p> <p>Notable Products and Performance Outcomes</p> <ul style="list-style-type: none"> The grantee and partners accomplished the following CDR related activities: <ul style="list-style-type: none"> Increased local community awareness of CDR by creating and implementing outreach strategies; Increased regional partners and referrals network; Developed processes to counsel caregivers about respite and other community supports; Informed, assisted, and enrolled eligible caregivers into the CDR program; Collected evaluation data demonstrating the merits of the CDR program. 	<p>State and Community Partners/State Respite Coalition/Organization Role</p> <p>ICOA, Idaho Caregiver Alliance (ICA) and the AAA aging network worked in partnership to increase capacity and collaboration among an array of other important partners including: the Idaho Department of Health and Welfare Medicaid, Children’s Behavioral Health, Idaho Parents Unlimited, Blue Cross and Molina of Idaho, health and behavioral providers, healthcare delivery systems, Jannus, AARP and many more. Key partners contributed to fact finding and evaluation of</p>

- The Southwest Area Agency 3 (with three bilingual staff members) and ICA focused on reaching and supporting Hispanic and grandparents/kinship care populations.
 - Enrollment increased 60% in a six-month period as a result of their outreach and support efforts.
- During September 2020 – August 2023, Idaho AAAs served 425 caregivers providing 26,306 hours of consumer-directed respite and other supports.
- Carryover funds allowed ICOA to contract with Rays for Rare, a nonprofit organization that provides uplifting pediatric palliative and supportive care.
 - These funds supported the provision of 1,737 hours of respite to 128 medically fragile children and their families from March 2023 – February 2024.

Objective 2: Expand access to information about the value of respite and respite care resources to lifespan caregivers through established and new information access points including: Area Agency on Aging/Aging and Disability Resource Centers (AAA/ADRC), the Idaho Caregiver Alliance (ICA), Family Caregiver Navigator (FCN), churches, and employers.

Notable Products and Performance Outcomes

- The ICOA and ICA expanded the No-Wrong-Door entry points for lifespan caregivers through ICOA, the AAAs/ADRCs, Idaho Parents Unlimited, 2-1-1 Careline, ICA, and FCN.
 - Their efforts included an active ICA website, monthly newsletter, and social media presence dedicated to lifespan caregiving.
- ICOA contracted with four AAAs, ICA, BSU-CSA and Rays for Rare to increase local community awareness of the CDR and respite programs through outreach and marketing strategies including: distributing flyers to clinics/hospitals and libraries; presenting information to organizations across the state such as tribal communities and employers (Hewlett Packard, Micron, and Boise State University); posting radio ads; providing staff trainings; issuing monthly newsletters; using social media, conferences, quarterly meetings, family events, Hispanic kinship care resources and committee development, fundraisers, and Idaho educational legislative luncheons and updates to inform and advocate.

Idaho caregiver needs and the effectiveness of ICOA and the ICA. The grantee and key partners expanded resources and connections with the development of the ICA website, resource library, quarterly meetings, monthly newsletters, legislative updates and three navigator project advisory committees. The grantee and partners also increased outreach to and promoted cultural awareness of Idaho's Hispanic community.

Aging and Disability Resource Center Role

ADRCs were key partners across multiple grant activities, especially in expanding access to information about the value of respite and ways to access respite resources. Evaluation data was used to help understand how the system affected caregiver access and to guide the grantee and partners in streamlining referrals and enrollments in ADRC systems.



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

Lifespan Respite Care Program



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

Funding Period: September 1, 2020 – August 31, 2023

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

Primary Goal: **Strengthen New York State’s Lifespan Respite Care system through expanded respite services, new partnerships, and targeted statewide outreach to provide a sustainable, coordinated respite care system that supports caregivers across the age and disability spectrum.**

Key Performance Measures	Notable Achievements
<p>The grantee collected systems-analysis data documenting their enhanced policy framework and numerical data documenting improved service delivery for underserved populations. They collected survey data documenting improved well-being experienced by caregivers receiving volunteer respite; improved standardization of respite resources in the NY Connects Resource Directory; and enhanced knowledge about working caregivers among businesses. New products and resources included: New York State Caregiving and Respite Coalition (NYSCRC) monthly newsletter; Caregiver Guide for Businesses; an online respite provider training curriculum; a respite provider monitoring tool; a caregiver simulation leader manual; a video about the respite voucher program; an application packet with satisfaction survey for NYSCRC’s respite voucher program; a video describing the importance of supporting working caregivers; a NY Connects Resource Directory form; a resource brochure for working caregivers; and a final report that included an independent program evaluation.</p>	<p>New York’s Core Team continued to build a sustainable respite care system for caregivers across the age and disability spectrum throughout New York State. Program and policy improvements made possible through this grant included: increased capacity of the New York State Caregiving and Respite Coalition (NYSCRC); addressed gaps in respite care availability through targeted mini-grant funding opportunities and the Respite Voucher program; piloted and implemented an online respite care provider training program; educated the public and businesses through the Working Caregiver Initiative; and improved the availability of caregiving and respite resources within the NY Connects Resource Directory.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1. Increase the number and types of partnerships to strengthen New York State’s Lifespan Respite Care system.</p> <p>Notable Partnerships and Expansion Activities</p> <ul style="list-style-type: none"> The grantee brought together federal, state, and local resources and funding streams to support, expand, and streamline availability and accessibility of respite services. NYSOFA, NY Connects, Monroe County Office for the Aging (MCOFA), Lifespan of Greater Rochester, and NYSCRC worked in partnership to form a Core Team. The Core Team worked with key collaborators to build a statewide Lifespan Respite program that is fully integrated into New York State’s long-term services and supports (LTSS) system and is sustainable beyond the period of federal funding. 	<p>State and Community Partners</p> <p>As described in Notable Achievements and under Objective 1, the grantee expanded partnerships and community partners collaborating in systems building and coordination, and in sustainability planning. In addition, a Core Team of key partners worked with key collaborators in strengthening leadership and coordination and assuring full integration of respite into</p>

Objective 2: Expand volunteer respite care services, training, and oversight across the age and disability spectrum.

Notable Products and Performance Outcomes

- With state and local partners, the grantee recruited and trained volunteer respite workers, and provided additional caregiver supports and services.
- NYSCRC offered three cycles of Lifespan Respite mini-grants that focused on developing or expanding volunteer-based respite care programs.
- To address a shortage of available respite services, NYSOFA expanded its caregiver-directed respite model under the National Family Caregiver Support Program (NFCSP). This method of service delivery provides family caregivers and the individuals they care for more control over their care, while also expanding the availability of respite services statewide.

Objective 3: Expand outreach strategies to address underserved populations with respite care and build emergency respite capacity.

Notable Products and Performance Outcomes

- In 2021, NYSOFA and NYSCRC launched a workgroup to develop a more comprehensive caregiver-directed service delivery model for NYSOFA's Area Agencies on Aging (AAAs) as well as a respite voucher program to be administered by NYSCRC. The workgroup focused on: core considerations; determining eligibility and funding prioritization; emergency respite; application processes and forms; capacity and marketing; program evaluation; and data collection.
 - In addition to professional recommendations, NYSOFA sought perspectives of informal caregivers during a series of focus groups held in June 2021. Caregivers participating in the focus groups provided valuable information that informed the development of the caregiver-directed respite model.
 - In 2022, NYSOFA issued NFCSP Standards that informed AAAs about expansion of the optional caregiver-directed respite service delivery model, including requirements for implementing the model. AAAs became eligible to offer caregiver-directed in- or out-of-home respite care using either a fiscal intermediary or respite vouchers. This expansion allowed AAAs to partner with NYSCRC to administer the AAAs' voucher program with NFCSP funds. To date, 20 AAAs have been approved to offer caregiver-directed respite using NFCSP funds. These additional options have improved and increased respite care services for underserved populations across New York State.
- NYSCRC implemented a respite voucher model to serve kinship and other informal caregivers caring for persons with chronic conditions who were not eligible for other public funding. Eligible caregivers received a voucher of up to \$600 to pay for respite care. Caregivers chose to receive respite through an agency or hired individual respite providers, and chose to pay providers up front and receive reimbursement, or have NYSCRC pay provider(s) directly.
 - Since its launch in January 2022, 326 unduplicated caregivers received respite vouchers totaling \$226,320.55. Of those caregivers completing a satisfaction survey after using a voucher, 98% reported that the voucher program helped to reduce their stress.
- The Core Team worked to build capacity for emergency respite within New York State and support caregivers experiencing emergencies such as a natural disaster, an unplanned hospitalization, or a public health emergency. NYSCRC developed a dedicated page on its website for emergency respite. Through the NFCSP Standards, NYSOFA permits AAAs, once they have developed policies and procedures defining and setting parameters for

New York State's long term-services and supports.

State Respite Coalition/ Organization Role

The grantee has a strong partnership with the New York State Caregiving and Respite Coalition (NYSCRC). They worked together on all aspects of the Lifespan Respite Grant, and more broadly in New York State, to accomplish all activities described in this summary.

Aging and Disability Resource Center Role

NYSOFA has invested significant resources into the development and maintenance of the NY Connects Resource Directory, an online statewide directory available to the public. The Resource Directory provides information on providers and a wide range of programs, services, and supports (including respite care services) for individuals in need of LTSS and their caregivers. To help improve standardization of respite resources in the NY Connects Resource Directory, the Core Team developed a standardized template that caregiver and respite organizations could use to request to be added to the NY Connects Resource Directory.

emergency respite, to offer emergency respite without requiring that caregivers first complete an assessment and usual paperwork.

Objective 4: Expand workforce initiatives with businesses in supporting working caregivers.

Notable Products and Performance Outcomes

- The grantee launched an initiative to explore the impact of caregiving on public and private businesses; help human resources departments recognize the impact caregiving has on employees; provide them with helpful resources; understand the perspective of the employed caregiver; link caregivers to resources; to make caregiving a statewide issue for all systems.
 - NYSOFA and NYSCRC collaborated with the University of Wisconsin to tailor its web-based Employed Caregiver Survey to the needs of New York State. NYSOFA modified the Wisconsin survey and made it available on the NYSOFA website. Data collected from 700 respondents showed:
 - ✓ 56% of employees assist the individual(s) they care for 15 hours or more per week.
 - ✓ 42% of employees have not been able to take a vacation in over two years due to their caregiving responsibilities.
 - ✓ Caregivers noted the following impacts on their work: arriving late (51%); leaving work early (68%); missing days of work (70%); being unable to stay focused at work (64%); and responding to emergencies during the workday (65%).
 - A separate survey developed for New York State employees yielded results from more than 2,500 respondents:
 - ✓ 52% of New York State employees provide eight or more hours of care per week.
 - ✓ 63% of New York State employees have had to use personal time to fulfill their caregiving responsibilities.
 - ✓ State employees who are caregivers noted the following impacts on their work: leave work early (65%); miss days of work (60%); respond to emergencies or calls during work hours (53%); and rearrange their work schedule (51%).



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

Lifespan Respite Care Program



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

Funding Period: September 1, 2020 – August 31, 2023

Contact: Aleatha Dickerson at aleatha.dickerson@oha.ri.gov

Primary Goal: **Further integrate, enhance, and sustain a statewide system of Lifespan Respite services across all populations.**

Key Performance Measures	Notable Achievements
<p>Healthcentric Advisors (HCA), a key partner, designed and deployed a student respite locator tool that collects essential information from each participating nursing student necessary for matching them with caregivers. The tool includes the following key components or characteristics: student information form; caregiver and care recipient forms for Catholic Social Services (CSS)¹ to organize care recipient information from the CareBreaks application and assist faculty in matching families with volunteer nursing students; the ability to link students, caregivers, and care recipients in the online portal; access for nursing faculty to log in and view their students and available caregivers; and user guides for CSS and nursing faculty, with step-by-step instructions for using the student respite locator tool.</p>	<p>The formally incorporated Family Caregiver Alliance of Rhode Island (FCARI) continued to strengthen its role as a resource and advocate for caregivers in the state by: disseminating the first Rhode Island State Plan to Support Caregivers and working with partners and interested organizations to advocate for the implementation of the plan; expanding membership of the FCARI’s Advisory Committee; continued maintenance and improvement of the FCARI website; planning and hosting the annual Family Caregivers Conferences; and working with OHA, United Way of RI (UWRI) 2-1-1, and the Point, the Rhode Island Aging and Disability Resource Center (ADRC), to ensure families have access to comprehensive information and resources for respite services, caregiver training and supports, and assistance with respite application preparation.</p>

¹ Catholic Social Services of Rhode Island (CSS) used federal Lifespan Respite funds to hire a new coordinator to work directly with students and caregivers.

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1. Enhance the Rhode Island student nursing respite workforce development initiative among higher education nursing programs in the state.</p> <p>Notable Products and Performance Outcomes</p> <ul style="list-style-type: none"> • During the grant period, the number of nursing schools participating in the initiative increased from four to five. • For each semester of all three grant years, Rhode Island College (RIC), University of Rhode Island (URI), the New England Institute of Technology (NEIT) and Salve Regina University (SRU) nursing programs placed between eight and 10 nursing students as respite providers to eligible families under the program. • For each semester in years two and three of the grant, the Community College of Rhode Island (CCRI) placed between eight and 10 nursing students as respite providers to eligible families enrolled in the program. A total of 80 families received respite services under the state-wide nursing student workforce initiative during the grant funding period. 	<p>State and Community Partners/State Respite Coalition/Organization Role</p> <p>During the project funding period, the Rhode Island Department of Human Services, Office of Healthy Aging (OHA), in partnership with the Family Caregiver Alliance of Rhode Island (FCARI); the United Way of Rhode Island, which houses the statewide Aging and Disability Resource Center (ADRC) known as the POINT; and other key collaborators worked to sustain, enhance, and improve a statewide Lifespan respite care system of services.</p>

- The nursing schools at CCRI, RIC and SRU had a total of 51 nursing students providing in-home respite services during the project period, with a total of 33 families or caregivers receiving volunteer respite services with many families participating during multiple semesters.
- New England Institute of Technology (NEIT) incorporated respite into the curriculum of their new “Licensed Practical Nursing” (LPN) program.

Objective 2: Continue to enhance the framework of the State’s respite program through the incorporated Family Caregiver Alliance of Rhode Island (FCARI).

Notable Products and Performance Outcomes

- NEIT faculty participated in the grant project and FCARI meetings.
- The FCARI created a State Plan Executive Committee to collaborate, implement, and measure the goals set forth in the RI State Plan to Support Family Caregivers.
 - The FCARI convened three workgroups which met every three to four weeks to address four focus areas: Policy and Legislation; Inclusion, Diversity, Equity, and Accessibility (IDEA); and website enhancements.
- The FCARI continued to plan and hold annual Family Caregivers Conferences.
- The FCARI continued to maintain and improve its website, including a caregiver resources home page with links to individual pages for caregivers of older adults, adults with disabilities, and children.

Objective 3: Improve awareness about respite services and access to respite services, to include continued funding of the CareBreaks respite program that was implemented under a previous Lifespan Respite grant.

Notable Products and Performance Outcomes

- The FCARI website links to resources including the CareBreaks respite program; the “Point,” Rhode Island’s Aging, and Disability Resource Center (ADRC); the “My Options RI” web site, the State of RI web site connecting older adults and adults with disabilities with “Person Centered Options Counseling” (PCOC) for Long Term Services and Supports to remain in the community; and 2-1-1 for basic information and resources.
- The University of Rhode Island (URI), School of Nursing implemented and expanded their Pediatric Group Respite Program, an on-campus weekly group respite program serving families with children with special healthcare needs.
 - Nine to 20 children participated in 43 group respite events.
- The Catholic Social Services of RI (CSS) served moderate- to low-income families by providing cost share assistance with Lifespan Respite funding under the CSS CareBreaks respite program.
 - CSS reported that 120 unduplicated families received respite services from the CareBreaks program during the three-year project period.

Program Flexibilities and Supports Offered in Response to Ongoing COVID-19 Pandemic

- Each RI nursing program identified strategies to safely resume the volunteer nursing student respite services in the Fall of 2020:
 - The Salve Regina University (SRU) resumed in-home respite services, working with families who would accept nursing students into their homes. Forms about COVID-19 were provided to both families and students. COVID-19 symptoms were also reviewed at the time of each respite service visit.

Aging and Disability Resource Center Role

The Family Caregivers Alliance Rhode Island (FCARI) website provides links to resources, including Rhode Island’s Aging, and Disability Resource Center (ADRC).

- The University of Rhode Island (URI) offered group respite events during both the Fall 2020 and spring 2021 semesters.
- OHA and CSS distributed care packages with personal protective equipment (PPE), including masks, gloves, hand sanitizer, and COVID tests to families participating in the nursing student respite initiative.
- OHA, Healthcentric Advisors, and UWRI expanded the use of social media and marketing campaigns to increase awareness of caregiver services, to address the lack of in-person outreach opportunities.



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

Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Tennessee Commission on Aging and Disability (TCAD)**

Funding Period: September 1, 2020 – August 31, 2023

Contact: Shelly Hale at shelley.hale@tn.gov

Primary Goal: **Expand and maintain a statewide coordinated lifespan respite system that built on the previously established infrastructure, and to respond to the needs of caregivers determined by client assessment and community conversations during the previous grant cycle.**

Key Performance Measures	Notable Achievements
<p>Indicators used to measure performance included: intake and assessment data from the web application; percentage of caregiver satisfactions surveys, including data on caregiver stress reduction and repeated service use; unique website hits; and the number of calls to the Respite Helpline. Products produced included postcards to caregivers in all 95 Tennessee counties; a monthly newsletter for caregivers and other interested organizations; a caregiver satisfaction survey for Tennessee Respite Coalition (TRC) consumers; social media posts for the general public; and a flyer targeting parents of children on the autism spectrum.</p>	<p>During the height of the COVID-19 pandemic, the TRC made significant strides to ensure that family caregivers were provided respite in unique and groundbreaking ways. Assistance provided included care packages to 94 caregivers in order to increase access to technology and much needed personal protective equipment. Other pandemic work included mini grants to provide caregivers a “non-traditional” break; the development of a Caregiver Mentoring Program; online support and discussion group; and electronic care packages that included self-care activities.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1. Merge the Tennessee Respite Coalition website and the TNRecharge website to create a centralized respite resource.</p> <p>Notable Products and Performance Outcomes</p> <ul style="list-style-type: none"> The TRC Website and TNRecharge websites merged to create a centralized respite resource in Tennessee. <p>Objective 2: Create a web application to make accessing TRC respite services easier for caregivers.</p> <p>Notable Products and Performance Outcomes</p> <ul style="list-style-type: none"> The TRC web application was developed. Approximately 50% of users utilized the app to upload their verification documents. <p>Objective 3: Digitize TRC intakes, service planning, assessment, and management processes.</p> <p>Notable Products and Performance Outcomes</p> <ul style="list-style-type: none"> The TRC intake process was digitized and 75% of intakes and assessments were accomplished digitally. 	<p>State and Community Partners/State Respite Coalition/Organization Role</p> <p>The long-standing partnership between the Tennessee Commission on Aging and Disability (TCAD) and the Tennessee Respite Coalition (TRC) formed the framework for collaborative work toward their shared goal of improving the quality of life for caregivers across Tennessee.</p> <p>Aging and Disability Resource Center Role</p> <p>The nine Area Agencies on Aging and Disability in Tennessee serve as the Aging and Disability Resource Centers (ADRC) within the state. Staff at each ADRC are trained to provide information and referral to the Tennessee Respite Coalition for caregivers in need of respite services.</p>

Objective 4. Increase the availability of respite vouchers for all caregivers across Tennessee.**Notable Products and Performance Outcomes**

- Respite vouchers were provided to 200 caregivers per year of the project, with a total of 600 vouchers used by caregivers.
 - Of caregivers using voucher respite services, 80% reported a reduction in stress and the desire to use respite vouchers again.
- Utilizing the services of InLab and Salesforce, a web app was created to allow caregivers the opportunity to enroll in the Respite Voucher program from their smartphone, tablet and computer. Prior to the web app, caregivers had to call TRC and schedule a time to complete an intake.
- TRC worked with Crenshaw Technologies to create a texting program to provide caregivers with pertinent information about their respite vouchers.
 - Caregivers now receive a monthly text notifying them of their remaining respite voucher balance and the date the funds must be spent by.
 - Caregivers also receive a text when their check is mailed after submitting their respite voucher so they know when they can anticipate receiving funds.

Objective 5. Increase access to the Respite Helpline.**Notable Products and Performance Outcomes**

- A postcard campaign was conducted which helped to increase the number of calls coming into the Respite Helpline.
 - Calls to the Statewide Respite Helpline increased by 200 calls annually from a baseline of 1,118 calls.
- Three hundred and thirty-nine events were held during the same time period with materials distributed.

Program Flexibilities and Supports Offered in Response to Ongoing COVID-19 Pandemic

- TRC provided care packages to 94 caregivers to increase access to technology and personal protective equipment, including spiral-bound copies of ARCH's *Providing and Receiving Respite Care Safely During the COVID-19 Pandemic*.
- TRC provided mini grants to provide caregivers a “non-traditional” break, the development of a Caregiver Mentoring Program, online support and discussion group, and electronic care packages that included self-care activities.



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

Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Wisconsin Department of Health Services (WI DHS)**

Funding Period: September 1, 2020 – August 31, 2023

Contact: Lynn Gall at lynn.gall@wisconsin.gov

Primary Goal: **Expand and strengthen the availability and accessibility of high-quality, person-centered respite services to caregivers, regardless of age or special need of the care recipient.**

Key Performance Measures	Notable Achievements
<p>Each stated objective of the Lifespan Respite Grant project was supported by measurable outcomes and enumerated indicators for determining success. Process evaluation was used during the development phase of each initiative or activity contained within an objective, including needs assessments related to respite availability throughout the state, as well as needs and preferences specific to underserved populations and communities. Workplan activities for each objective and indicator were monitored throughout the funding period for timeliness, effectiveness, and outcomes, and adjustments were made to ensure successful completion. Outcome measures including enumeration of products used, populations reached, workshops and trainings attended, and resulting knowledge acquired are described in brief in this summary for each of the projects' three objectives and supporting outcomes.</p>	<p>In order to develop and provide respite information, resources, respite funding, and new programs to underserved populations through partner agencies, the Respite Care Association of Wisconsin (RCAW) increased partnerships with agencies serving Latinx communities, Native American Tribes, relative caregivers, and rural communities. After determining unique needs for each population, RCAW created marketing materials specifically for each population and identified programs and agencies serving underserved populations that could be served by a new grant initiative. RCAW received 110 grant applications and funded 28 programs across Wisconsin serving rural communities, African American, Hmong, and Latino/ Hispanic families, tribal nations, LGBTQ+ individuals, individuals at risk for abuse and neglect, grandfamilies, siblings, and low-income families. More than 430 individuals received more than 3,200 hours of care under this grant initiative.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1. Increase the number of training opportunities available to respite providers.</p> <p>Notable Partnerships, Products and Performance Outcomes</p> <ul style="list-style-type: none"> • Provide trained providers access to specialty training and continuing education. <ul style="list-style-type: none"> ▪ This project shared its core training course, the Respite Care Provider Training, with other states across the nation. ▪ Providers requested access to RCAW's partnership with the College of Direct Supports (offering 45 different online training courses) or to RCAW's partnership with the UW Oshkosh Center for Community Development, Engagement, and Training (CCDET) online Dementia Training. Providers received funds to pay registration fees for conferences and webinars related to respite or care for persons with disabilities. 	<p>State and Community Partners/State Respite Coalition/Organization Role</p> <p>The Wisconsin Department of Health Services (WI DHS) and the Respite Care Association of Wisconsin (RCAW) were key partners in this project. As part of this project, new systems were created, resources were developed, and research was conducted about the state of respite in Wisconsin. This was particularly important due to the COVID-19 pandemic to learn how changes in the availability and service</p>

- Through presentations at the National Lifespan Respite Conference, Dementia Courses, and the College of Direct Supports, 126 training opportunities were completed, and an additional 2,000+ views of webinar recordings occurred.
- Translate RCAW's Respite Care Certificate Program into Spanish.
 - All courses in the Respite Care Provider Training have been translated into Spanish. A pilot project requirement was a 100% pass rate on the training's final test, with learners having the opportunity to review information and retake the final test as needed. The average score on the pre-test was 54.44%, and the average score on the post-test was 100%.

Objective 2: Enhance a sustainable, coordinated statewide system of respite resources and programs for all family caregivers.

Notable Partnerships, Products and Performance Outcomes

- Establish a Statewide Project Advisory Committee (PAC) of key individuals and organizations that represent populations across the lifespan.
 - The PAC formed was comprised of long-term care professionals, state Department of Health Services staff, family caregivers, self-directed consumers, and representatives from institutions of higher education and tasked with reviewing project activities and assisting in planning and implementing the WI Lifespan Respite System.
 - PAC members developed an Annual Respite Summit model, and three Wisconsin Respite Summits were held during the funding period. Interactive feedback was garnered, documented, and shared.
- Upgrade RCAW's current Respite Registry and database tracking system.
 - The grantee transferred its registry and database tracking system to the Gnosis database system, allowing RCAW to build infrastructure to continue its programs efficiently and to establish a new function called Respite Connections. Respite Connections allows family caregivers to post a listing when they need respite, and respite providers on the Registry can search listings by county and age to find respite opportunities.
- Develop and implement a public awareness campaign for RCAW.
 - RCAW created a Benefits of Respite flyer used throughout the state that provides information about respite and shows caregivers ways to use natural supports. RCAW also provided informational webinar sessions and virtual conferences to reach family caregivers and providers where they were. Inquiries for RCAW grant programs increased 1,172%.
- Develop a sustainable system for ongoing assessment of Wisconsin's current state of respite and needs.
 - An evaluator developed and launched an online survey in 2022, and data was collected and presented on a RCAW webpage. A similar survey will be conducted every other year.

Objective 3: Create new respite programs throughout the state.

Notable Partnerships, Products and Performance Outcomes

- Develop and implement an instructor-led training in building a business plan to start a respite agency or program.
 - The Bringing Respite to Your Community Workshop was created as a 6-week workshop that included online self-paced lessons; face-to-face Zoom meetings with an instructor; and discussion boards. Nine sessions were held with 68 learners completing the workshop.

delivery of respite services during the pandemic affected the families in Wisconsin in real time and in longer term.

Other important partners in specific grant activities and initiatives are described within each of the three project objectives.

Aging and Disability Resource Center Role

RCAW educates ADRC staff about its programs and invites other respite agencies, ADRC's, and Wisconsin DHS staff to participate in RCAW workshop series and to share information statewide.

- Develop a student volunteer-based college/university model for respite care.
 - A high-quality Student Respite Provider Program toolkit that could help replicate student respite volunteer models across the country was developed. The Student Respite Collaborative was established in partnership with the ARCH National Respite Network and the Building Respite Evidence and Knowledge (BREAK) Exchange in order to provide a forum for academic partners and program staff involved in student respite programs to share ideas, best practices, and identify potential collaborative opportunities.

Program Flexibilities and Supports Offered in Response to Ongoing COVID-19 Pandemic

- During the COVID-19 pandemic, RCAW provided live 30-minute monthly webinars on a variety of topics that were posted on the RCAW YouTube channel for continued access.
- With COVID-19 supplemental funds, a fourth outcome was added to the project increase existing respite by dedicating PPE and other resources to programs affected by the pandemic.



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