

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