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

Funding Period: 2014-2017

Primary Goal: Continue building a coordinated and sustainable state Lifespan Respite Program that expands access to respite and is fully integrated into New York State’s Long Term Services and Supports System.

Key Performance Measures

Data collected on lifespan respite includes: number of trained volunteers providing respite to caregivers and families; and number of caregivers using NY Connects (a state funded information and resource initiative). Data on utilization of consumer-directed respite voucher model under the Older Americans Act (OAA) Title III-E program will be collected in future.

Notable Achievements

Lifespan Respite Program partners established a train-the-trainer program, using an evidence-model of respite provider training, to expand the workforce of volunteer respite providers across the state. Key partners also collaborated with other state agencies to establish Medicaid funding for the Caregiver Support Program as part of New York State’s Balancing Incentive Program (BIP) demonstration. This funding was provided to expand availability of services and supports to caregivers across the lifespan caring for Medicaid eligible individuals of all ages and disabilities. Respite services listings have been updated and caregiver-specific activities associated with respite services listings have been added to the NY Connects Resource Directory.

Key Objectives, Activities and Outcomes

Objective 1: Expand available respite by a workforce development initiative and protocols for respite voucher programs.

- In 2016, the New York State Caregiving and Respite Coalition (NYSCRC) Director and a Lifespan of Greater Rochester partner trained to become Master Trainers for the Respite Education and Support Tools (REST) model. This enabled them to provide training to staff of organizations across the state, who in turn would provide training to volunteer respite providers.

- A mini-grant/application process was undertaken, and in September 2016 nine organizations received mini-grants to receive REST training and develop/expand volunteer respite programs: the Autism Society of the Greater Capital Region, Baker Memorial United Methodist Church, Caregiver Resource Center, Steuben County Faith In Action Program, Home Away from Home Drop-In Respite, Kinship Caregiver Program’s Leadership Training Institute, Mercy Care for the Adirondacks, United Cerebral Palsy Association of the North County, and Parma Baptist Community Church. By end of 2017, 3 master trainers, 100 trainers, and 100 companion volunteers were trained in REST in 26 counties.

Coalition, ADRC and Community Partners

State Respite Coalition/Organization Role

- New York State Caregiving and Respite Coalition (NYSCRC), hosted by Lifespan of Greater Rochester, was established through the original federal Lifespan Respite grant and has become a valuable, well known caregiving and respite resource across the state.

Aging and Disability Resource Center (ADRC) Role

- New York State’s ADRC/No Wrong Door (NWD), New York Connects, has primary responsibility for maintaining the NY Connects Resource Directory of
• During 2017, three Caregiver Simulation sessions were held and attended by 45 to 60 persons at each session. Participants received training that enhanced understanding of caregiving responsibilities and stress; knowledge of community services; day-to-day caregiver experiences; and how the aging population impacts the need for services.

**Objective 2: Integrate the Lifespan Respite Program into the State Long Term Services and Supports System (LTSS) and into the NY Connects Resource Directory database.**

• NYSOFA team members worked closely with other state agencies in developing the state plan for New York’s Medicaid LTSS Balancing Incentive Program (BIP), and specifically the BIP Caregiver Support Program which was launched in 2016, serving individuals in 39 counties across the state. This program, which utilized Medicaid funds for respite and support options for caregivers across the lifespan who are caring for individuals of all ages and disabilities and are Medicaid eligible, coordinated closely with ongoing programming administered by NYSOFA.

• NYSCRC updated its website [http://www.nyscrc.org/](http://www.nyscrc.org/) during 2017 and continued to build content and create a go-to place for information tailored to informal caregivers and the professionals who serve them.

**Objective 3: Develop a Statewide Action Plan for Lifespan Respite Care sustainability.**

• The NYSCRC Director conducted extensive outreach to build connections within the caregiving network. During the first half of the grant, the NYSCRC had reached out to more than 1,000 aging and disability groups across the state to invite interested groups and individuals to participate in the continuing development of the NY Lifespan Respite Program. An advisory committee consisting of 22 members was established in 2016 including stakeholders from the fields of aging, Alzheimer’s disease, mental health, developmental disability, and child and family services sectors. The committee efforts focus on advocacy, website updates and sustainability of the statewide Lifespan Respite Program.

• NYSCRC also distributes monthly newsletters to approximately 800 individuals and organizations, hosts a website, and holds an annual conference that brings together state and local agencies, family caregivers, and the professionals who support them.

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**State and Community Partners**

• New York State Office for the Aging (NYSOFA) administers the federal Older Americans Act and OAA Title III-E, NY Connects (a state funded information and resource initiative), and other state-funded long-term services and supports. NYSOFA is also the lead agency for the NY State Family Caregiver Council and is co-chair of the New York State Coordinating Council for the Services Related to Alzheimer’s disease and Other Dementias. In addition to housing the Project Coordinator, an internal team that includes NYSOFA’s executive management and staff from all agency divisions is involved in all aspects of building New York’s Lifespan Respite Program.

• NY Connects

• New York State Caregiving and Respite Coalition

• Monroe County Office for the Aging and Adult Services (MCOFA). In addition to being the administering fiscal agent for the federal grant, the director of MCOFA participates in the NY Lifespan Respite Project core team and acts as the liaison to the New York State Association of Area Agencies on Aging to actively assure coordination with the local AAAs.
Lifespan Respite Grantee Lead Agency: New York State Office for the Aging (NYSOFA)

Funding Period: 2017-2020

Primary Goal: The Lifespan Respite Core Team (Core Team) will build upon prior and current Lifespan Respite initiatives by engaging key stakeholders to increase and expand access to respite services statewide, and enhance partnerships for education, outreach, and service provision to advance development of a Lifespan Respite Care System.

### Key Performance Measures

NYSOFA documents statewide implementation of the REST (Respite Education and Support Tools) training model (with a goal of 100%); 30% increases in REST Companion volunteers (with a goal of 30% over baseline); increases in the number of individuals that receive information and assistance on caregiver supports through NY Connects; increases in knowledge about caregiving through Caregiver Simulations among nine higher education institutions and three private sector business entities; and the completion of a qualitative review of respite listings in the NY Connects Resource Directory.

### Notable Achievements

The NY Connects Resource Directory includes regular data feeds on long-term services and supports (LTSS) providers and programs from the NY Department of Health, Office for People with Developmental Disabilities, Office of Mental Health, and Office of Alcoholism and Substance Abuse Services, adding to the aging network listings already in the Directory for a current total of over 72,000 program listings. This activity is part of NY Connects’ expansion to a No Wrong Door (NWD) system that now provides statewide coverage of information and assistance on LTSS to individuals across age and disability types, their caregivers, and helping professionals (https://nyconnects.ny.gov). The New York State Caregiving and Respite Coalition (NYSCRC) developed a new brochure highlighting its mission, information about the Virtual Resource Center, and other available services.

### Key Objectives, Activities and Outcomes

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

- New York State uses a multi-strategy approach to assisting families and caregivers by supporting respite through expansion of the evidence-supported REST program. Additionally, NYSOFA assisted in outreach efforts to RSVP programs in targeted geographic areas to further expand the REST model across the state.
- In December 2018, NYSCRC awarded two mini-grants of $3,500 each to further develop and/ or expand the Volunteer Respite programs in faith-based organizations. Awardees are Grace Lutheran Church in Broome County, and Greece Baptist Church in Monroe County. Grace Lutheran is developing a “Senior Care Respite Program,” which will provide an opportunity for caregivers to drop off their loved one at the program once a month, providing relief for caregivers in the Vestal, NY area. Greece Baptist Church is developing a “Give Me a Break” Drop off Respite program that will also be hosted monthly and serve caregivers in Greece,

### Coalition, ADRC and Community Partners

**State Respite Coalition/Organization Role**

- The New York State Caregiving and Respite coalition, part of the core team guiding and administering the lifespan respite grant, is also a key partner in establishing a Lifespan Respite Resource Center that will make available a suite of evidence informed/evidence-based training services, the Caregiver Simulation model for education with new partners in higher education and the private sector, as well as other materials and respite-related resources.
Key Objectives, Activities and Outcomes

NY: Both dedicated faith communities are committed to using REST to train and support their volunteers.

Objective 2: Expand available respite services statewide through formalizing a caregiver-directed respite model.

- NYSOFA reconvened its consumer-directed work group previously formed under the 2014-2017 Lifespan Respite Initiative and is well underway in developing a formal “caregiver-directed” respite services model using funds under the Older Americans Act (OAA) Title III-E program. This optional model for Area Agencies on Aging (AAAs), will offer greater flexibility with a person-centered approach for caregivers to identify and help address their respite needs.

Objective 3: Expand access to caregiver services through improved respite listings in the NY Connects Resource Directory across age and disability types.

- NY Connects, New York’s No Wrong Door “hub”, provided consistent, comprehensive, locally-based information on long-term services and supports to consumers, caregivers, and families to help them make informed choices, and assisted them in linking to services across service systems. During the first six months of funding, approximately 4,000 caregivers contacted NY Connects for assistance each month, and more than half of those caregivers received information on available respite services. Data show that caregiver supports continue to rank in the top third of topics being requested in NY Connects.

Objective 4: Implement and continue to update the Statewide Action Plan for Lifespan Respite sustainability.

- The Core Team hosted a Lifespan Respite Sustainability State Summit with invited participants to undertake strategic planning work on Lifespan Respite Sustainability during the Fall, 2018.
- The NYSCRC Director continues to ‘build’ the Lifespan Respite Virtual Resource Center (VRC), housed on the NYSCRC Website by adding new resources and training tools as identified through partnerships with key stakeholders. New resources added to the VRC this reporting period include the AARP Leading Age Change Report; the Legislative Update on Care Corps Demonstration Act; listings of caregiver workshops hosted by Lifespan of Greater Rochester; Generations United Grandfamilies Fact Sheet; and ARCH Fact Sheet for caregivers of persons with Intellectual Developmental Disabilities.

Coalition, ADRC and Community Partners

Aging and Disability Resource Center (ADRC) Role

- Aging and Disability Resource Center Role
- NYSOFA, a core team member for this grant, is the state agency responsible for administering programs under the federal Older Americans Act (OAA) and for administering NY Connects (ADRC/NWD), and other state-funded LTSS programs. New York Connects has primary responsibility for maintaining the NY Connects Resource Directory of community-based long-term services and supports.

State and Community Partners

- The Lifespan Respite Core Team (Core Team) is comprised of the: New York State Office for the Aging (NYSOFA), Monroe County Office for the Aging (MCOFA), New York State Caregiving and Respite Coalition (NYSCRC), and New York State’s ADRC/NWD (NY Connects).
- Additional partners include: faith-based organizations to bring respite into underserved communities; RSVP to help build a pool of respite volunteers; and NYSCRC and higher education to establish a Lifespan Respite Resource Center.

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