



# **New York State 2018 Lifespan Respite Sustainability Summit**

## **Final Report**

### **Executive Summary**

**October 18, 2018**

**Summit Partners:**

*Report Revised 6/2019*

Administration on Community Living (ACL)  
ARCH National Respite Technical Assistance Center  
Albany Guardian Society  
AARP New York  
New York State Office for the Aging (NYSOFA)  
New York State Caregiving and Respite Coalition (NYSCRC)  
New York State’s ADRC (NY Connects)  
Monroe County Office for the Aging (MCOFA)  
Lifespan of Greater Rochester, Inc. (Lifespan)

**New York Lifespan Respite Program:**

Deana Prest  
NY State Office for the Aging  
2 Empire State Plaza  
Albany, NY 12223  
Phone: (518) 486-2719  
[Deana.Prest@aging.ny.gov](mailto:Deana.Prest@aging.ny.gov)

**State Respite Coalition:**

Doris Green, MPA  
Director – NYS Caregiver and Respite  
Coalition  
Lifespan of Greater Rochester  
1900 S. Clinton Avenue  
Rochester, NY 14620  
Phone: 585-287-6393  
[dgreen@lifespan-roch.org](mailto:dgreen@lifespan-roch.org)

Web: [www.nyscr.org](http://www.nyscr.org)

**Respite Program Evaluator:**

Thomas V. Caprio, MD, MPH, MS  
Finger Lakes Geriatric Education Center  
University of Rochester Medical Center  
[Thomas\\_Caprio@urmc.rochester.edu](mailto:Thomas_Caprio@urmc.rochester.edu)



The ARCH Lifespan Respite Technical Assistance Center is supported, in part, by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

## EXECUTIVE SUMMARY

# Lifespan Respite Sustainability Summit

**Overview:** The **2018 Lifespan Respite Sustainability Summit** convened in Albany, New York on **October 18, 2018** under a partnership with Administration on Community Living (ACL), the ARCH National Respite Technical Assistance Center, the NYS Caregiving and Respite Coalition (NYSCRC) managed by Lifespan of Greater Rochester, Inc., the New York State Office for the Aging (NYSOFA) and the Monroe County Office for the Aging (MCOFA). This Summit was made possible by the generous support of the Albany Guardian Society and AARP New York. The Summit invited representatives across the age and disability spectrum, bringing together both caregivers and professionals. Representation was included from the Office for People with Developmental Disabilities (OPWDD), Department of Health (DOH), the Veteran's Administration (VA), New York State Office for the Aging (NYSOFA), Office of Children and Family Services (OCFS) and the Office of Mental Health (OMH) to provide insight into current respite services available across systems.

**Goal:** The Summit was aimed to connect policymakers, researchers, family caregivers, and statewide partners to exchange knowledge and expertise, leading to the development of a statewide strategy for strengthening the respite care system for all individuals and caregivers, across the lifespan.

**Purposes:** Strengthen state and community partnerships to sustain New York's Lifespan Respite activities; develop strategies to maximize use of existing respite resources; identify and leverage new respite funds; engage in sustainability planning; and generate innovative activities for future development.

**Objectives:**

1. To identify state-level policy and program needs and goals related to respite care services for children, adults and aging population.
2. To strengthen state and community partnerships to sustain Lifespan Respite activities.
3. To develop strategies to maximize use of existing respite resources.

**Key Findings:**

New York State has a rich array of resources for caregivers and has built a coordinated system for Lifespan Respite through: collaboration with stakeholders; leveraging the NYConnects No Wrong Door system for access to long term services and supports across all ages and disability groups, including respite resources and other supports for caregivers; and through the statewide engagement and dissemination of initiatives through NYSCRC. In addition, the New York State Caregiving and Respite Coalition, in collaboration with the ARCH National Respite Network and Resource Center and NYSOFA will host the 2019 National Lifespan Respite Conference in Buffalo, NY, April 30 - May 2, 2019, providing further opportunities for engagement and furthering the cross-discipline collaborations for effective service implementation.

## **Recommendations from Summit Participant/Stakeholders**

Through discussion with Summit participant stakeholders the following themes emerged as recommendations for sustainability planning:

- 1. Building Capacity:** Participants identified the need to increase the availability of respite services, including expansion of the REST model particularly to rural areas across the state, engaging more volunteers (see workforce below), increasing outreach in a culturally-sensitive manner to communities, and seeking greater engagement of faith-based communities and human services providers.
- 2. Workforce Development:** There is an identified need for improved trauma-informed care training for direct care workers, as well as enhanced behavioral health training for both caregivers and professionals. Participants advocated for greater outreach to students to participate in respite care, including creating incentives for nursing and social work students such as service-learning experiences and encouraging the receipt of college credits for working with respite programs. Student loan forgiveness for respite work and looking at direct care workers to have career opportunities including career ladders, enhanced pay scales, and training programs will benefit respite services.
- 3. Increasing Awareness and Service Utilization:** Participants recommended that broader marketing was needed to increase awareness of and eligibility for respite programs. There is also the need for greater engagement with the medical community, as many clinicians and health systems are unaware of resources to connect in the community. There is the recommendation to educate the public as to the “No Wrong Door Approach” to greater utilize NYConnects.
- 4. Enhanced Collaboration:** There was a general perception that respite services across systems are fragmented by funding streams and related requirements, and this creates a perception by consumers that it is difficult to navigate. Along those lines, recommendations were for the NY Connects Resource Directory to be more consistently updated with respite resources, and that discussions regarding respite be integrated into the Governor’s Health Across All Policies (HAAP) and Age Friendly projects. Participants recommended a greater focus on care coordination activities across state, aging services, and community service providers.
- 5. Enhanced Funding:** Participants recommended increased staffing within NY Connects, and also to focus on areas in which cost-savings to the system provided by receipt of respite care can be subsequently reinvested in the system to support expansion of respite services. A consistent theme was the need for better tracking outcome data, including the focus on health care outcomes for caregivers to support the ongoing expansion of respite care.
- 6. Policy/Legislative Initiatives:** Participants recommended more focus on inclusion of respite in public policy discussions and activities designed to expand access within health care and health care financing reform, including Medicaid and Medicare initiatives, such as through Business Acumen. Also recommended was the removal of barriers for dually diagnosed (medical/behavioral) children, teens, and adults.