Lifespan Respite Grant (2017-2020)
Report highlights - 9/1/17-2/28/18

The goal of the Lifespan Respite Grant (2017-2020) is to 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. Accomplishments made thus far include:

**NYSOFA/NY Connects**
- NYSOFA reconvened its consumer-directed work group previously formed under the 2014-2017 Lifespan Respite initiative. This work had been postponed until the NYSOFA Caregiver Program Coordinator Position was filled. Work is now well underway in developing a formal “caregiver-directed” respite services model using funds under the Older American Act (OAA) Title III-E (III-E) program, also known as the National Family Caregiver Supports Program. This optional model for Area Agencies on Aging (AAAs), but once complete, will offer greater flexibility with a person-centered approach for caregivers to identify and help address their respite needs. NYSOFA work group members have convened twice during the reporting period, and the group will continue to meet monthly until formal policies are fully developed and disseminated. This work will assist New York in achieving its objective of expanding available respite services statewide through formalizing a caregiver-directed respite model.
- NYSOFA assisted in outreach efforts to RSVP programs in targeted geographic areas to further expand the nationally recognized, evidence supported REST model across the state. These efforts generated an informational call with Suffolk County RSVP, where the NYSCRC Director provided an in-depth overview of the REST model and its associated benefits.
- NY Connects is New York’s No Wrong Door (NWD) “hub” to provide consistent, comprehensive, locally-based information on long term services and supports to consumers, caregivers, and families to help them make informed choices, as well as assistance in linking to services across service systems. According to NY Connects reports, during this Lifespan Respite grant reporting period, an average of 4,000 caregivers contact NY Connects for assistance each month, with more than half of these caregivers receiving information on available respite services. Additionally, reports show that caregiver supports continues to rank in the top third of topics being requested in NY Connects.
- NYSOFA’s Caregiver Program Coordinator, also program lead for the Lifespan Respite grant, coordinates monthly Webinars with various topics related to caregiving and respite for AAAs under OAA III-E. NYSCRC continues to be a standing agenda topic each month, offering opportunity for continual integration,
providing updates and/or announcements on NYSCRC's work. More than 220 individuals are invited to participate in each call, with monthly averages at 60 attendees. The calls are held as Webinars or conference calls, based on the topic and presenter. Regardless of the format used, each call is recorded and a link to access the recording is shared with invitees. For January's call, NYSCRC staff provided an overview of "Mindfulness for Caregivers", a new resource being added to the NY Lifespan Respite VRC. This example helps demonstrate the ongoing efforts made toward integration and sustainability of Lifespan Respite in New York State.

- At the National Respite Conference held in Huntsville, AL in October 2017, the Administration for Community Living sought volunteers to participate in a data work group being formed. The Lifespan Respite Program Director and NYSCRC staff volunteered and have been participating in the productive ARCH/ACL work group calls held over the last few months.

**New York State Caregiving and Respite Coalition (NYSCRC)**

- Continues to build its capacity, conduct outreach to the public, and develop implementation strategies to meet the Program deliverables.
- NYSCRC distributes its Newsletter and/or updates at least monthly to an estimated 800 people and/or organizations.
- NYSCRC raises awareness, educates, and increases the NYSCRC identity through social media and blogging. Currently, there are 178 Facebook followers and 157 Twitter followers of NYSCRC. Blogs are posted on the NYSCRC website, and highlighted in the monthly newsletter.
- Over this reporting period, the NYSCRC Director has worked with NYSOFA and NY Connects at the state level to design, create, and 'build' a New York Lifespan Respite Virtual Resource Center (VRC) to be developed by and housed virtually within NYSCRC. This VRC makes available a suite of evidence informed/evidence-based training services. The aim of the VRC is to further coordinate information about caregiving and respite training, technical assistance, and related materials. Initial tools that have been housed at NYSCRC and made available across New York include:
  - REST
  - Caregiver Simulation Model
  - Share The Care™
  - Mindfulness Based Stress Reduction
  - Charting the LifeCourse Tools™
  - Powerful Tools for Caregivers
  - Mindfulness Based Stress Reduction
- A Request for Applications (RFA) opportunity is currently being offered through the New York State Caregiving and Respite Coalition (NYSCRC) for 2-4 Mini Grants offering $2500-$5000 each for development and/or expansion of Volunteer Respite programs across New York State. This RFA opportunity is
open to local and/or regional agencies (e.g., offices for the aging, departments of social services, offices of mental health, developmental disabilities organizations, not-for-profit local and/or regional agencies, and faith-based organizations) located in New York State serving caregivers with care recipients of any age living in New York State. Completed applications must be sent by email by 5:00 pm on June 25, 2018.

- NYSCRC has made significant progress in outreach to faith based organizations. A collaborative team made up of members from NYSCRC, Faith in Action Steuben County, Steuben County Office for the Aging, CareFirst, and Finger Lakes Caregiver Institute have been working to identify strategies to promote supportive programs for caregivers through faith communities. Incidentally two of the members are also reverends, in addition to their agency roles. This group, which has been working together since fall 2017, held a “Memory Loss – A Call to Serve” gathering on Wednesday, April 11, 2018.

- NYSCRC has been participating in a StoryGrowing Initiative through the Western New York (WNY) Health Foundation. This initiative is based on the teachings of Andy Goodman of The Goodman Center. StoryGrowing WNY is a nine-month training program designed to help organizations harness the power of storytelling and nurture their organization’s growth through effective branding and communications training. Working directly with a variety of local professionals, the team learns how to balance emotional and rational messaging, target the right audiences, make efficient use of digital and social tools, and much more. NYSCRC seeks to support and educate caregivers on the topics of self-care, including using respite as a specific tool. Additional work in this initiative will be undertaken during the next six-months.

- NYSCRC held its annual conference October 2-3, 2017 in Albany, NY. The Conference theme, “Understanding and Effectively Engaging Caregivers” brought together state and local agencies, family caregivers, and the professionals who support them. This year’s annual conference spanned two days, with the first day offering attendees the opportunity to participate in a Caregiver Simulation. As noted, there were 60 individuals who participated in the simulation as a caregiver or care receiver, along with 20 volunteers who helped facilitate. The simulation concluded with a debrief session, highlighting the challenges and joys of caregiving. The main event for the annual NYSCRC conference was held the day following the Caregiver Simulation with 135 attendees, offering an expert group of speakers that provided valuable information from both their professional and personal experiences. Plans for 2018 include expanding the simulation into the business community across NYS.

- During the National Respite Conference held in Huntsville, AL in October 2017, New York was the recipient of the National “Vision” Award for training the most Respite Education and Support Tools (REST) trainers in the nation during 2017, which was highlighted in a NYSOFA press release. New York State has led a multi-strategy approach to assisting families and caregivers by supporting respite
through expansion of the evidence supported REST program. REST is a professionally designed train-the-trainer course that prepares individuals to conduct REST training, and the trainers then train individuals to be REST-trained Companions™ (volunteers).

- Respite Education and Support Tools (REST) Initiative - REST is a professionally designed 'Train-the-Trainer' course that provides respite education to those who will then go out and train others to be REST Companions™, also known as respite care workers or providers. Currently, there are: (as of 10/5/18)
  
  - 6 Master Trainers
  - 2 Regional Trainers
  - 132 Trainers
  - 185 Companions
  - Capacity to cover 49 counties