

Long Term Care Planning Project Meeting 3 Background Paper- *Family Caregiving Support*

Family caregivers, also known as informal caregivers, are the backbone of New York State's (State) long term care system. Typically, they are a relative, spouse, partner, friend, or neighbor, who provides countless hours of unpaid, often hands-on care or support for New Yorkers of all ages. Family caregivers for older New Yorkers help to ensure that they can age in place, either by providing direct care to a loved one in their own home or in the home of the care recipient.

According to the National Academies of Science, Engineering, and Medicine's *Families Caring for an Aging America* report, at least 17.7 million people in the United States are family caregivers for an individual 65 years of age or older with a significant health problem or disability.¹ By 2030, the same report indicates that 72.8 million – more than one in five U.S. residents – will be age 65 or older.² As the population ages the caregiver ratio, of adults able to provide care to an older adult, is projected to rise. In New York, the family caregiver ratio stands at seven available caregivers per person, with changes in demographics, this ratio is expected to decrease to nearly 4 to 1 by 2030.³

Without sufficient awareness of the myriad of support services that are currently available or the lack of some support services based on geography, many of the State's family caregivers may face higher levels of stress than non-caregivers.⁴ Studies have examined the burden and impact of caregiving on the caregivers' health, financial status, and well-being and have documented the need for greater access to relevant and affordable services, such as respite care, case management, legal services, counseling and mental health supports.⁵

Nationally, family caregivers may provide up to at least 20 hours of care per week, with many spending more hours a week providing care.⁶ Many have jobs, and it is not uncommon for family caregivers to encounter challenges at work – whether changing to part-time work, retiring early, quitting or being let go due to their caregiving responsibilities. This often results in financial struggles which may lead to lost wages or delayed retirement.

Family caregivers often pay out of pocket for caregiving expenses, including medications, transportation, personal care services, respite, and home modifications like grab bars, walk-in bathtubs, and chair lifts. According to a draft finding by SUNY Albany School of Public Health, family caregivers in New York spend, on average, approximately \$10,500 a year on caregiving expenses. Family caregivers who leave the workforce early to provide full-time care to a loved one can lose an average of \$304,000 in wages and benefits over the course of their lives.⁷

1 The National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*; 2016. National Academies Press.

https://www.johnahartford.org/images/uploads/reports/Family_Caregiving_Report_National_Academy_of_Medicine_IOM.pdf.

2 Ibid.

3 New York State Office for the Aging. <https://aging.ny.gov/ReportsAndData/CaregiverReports/InformalCaregivers/CGSurveyResults.cfm>.

4 Family Caregiver Alliance. <https://www.caregiver.org/caregiver-health>.

5 The Gerontologist, *Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies*; April 2015.

6 Northeast Business Group on Health, *Caregivers in the Workplace: A practical Guide for Employers*. https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving_Practical-Guide-FINAL.pdf.

7 MetLife Mature Market Institute. "The MetLife Study of Caregiving Costs to Working."

However, most family caregivers, including parents and grandparents, do not recognize or identify themselves as family caregivers, and thus never avail themselves to the benefits or services that they may need or be eligible for. Yet, while family caregivers often acknowledge their need for services like respite care and legal help, they do not know that such services are available or how to obtain them.

The State utilizes a variety of federal and state funding streams to serve caregivers, including federal funding through Title III-E of the Older Americans Act administered by the New York State Office for the Aging. Nationwide, the economic value of the care and services provided by family caregivers is estimated at \$470 billion a year.⁸ It is estimated that the value of the care and services voluntarily provided by family members is about \$32 billion annually.⁹ As the need for family caregivers grows, the need to support them will become even more urgent.

The State supports its 2.6 million family caregivers - who are providing 2.4 billion hours of unpaid care annually - through state and federal funding supporting the development and delivery of services and supports. According to the AARP 2017 Long Term Services and Support Scorecard, New York currently ranks number 11 in terms of support for family caregivers, but more can be done.

Federal and State Programs

The following provides background information on the federal and state level actions currently affecting family caregiver support.

Federal

National Family Caregiver Support Program (NFCSP, Title III-E)

The National Family Caregiver Support Program (NFCSP) provides funding to state units on aging to provide support to caregivers who care for a loved one in their home. Caregiver services under NFCSP include:

- Information about services available in local communities;
- Assistance in gaining access to services and resources in local communities;
- Individual Counseling, Support Groups and/or Caregiver Training services that are offered in the areas of caregiving, health, nutrition, and financial literacy and assist the caregiver in making decisions and solving problems related to their caregiving role;
- Respite Care is offered to allow caregivers to be temporarily relieved from their caregiving responsibilities. Services can be provided in the home, adult day service program, or an overnight stay in a residential care setting; and,

Caregivers," 2011. <http://www.caregiving.org/wp-content/uploads/2011/06/mmicaregiving-costs-working-caregivers.pdf>.

⁸ AARP Public Policy Institute. "Valuing the Invaluable: 2015 Update," 2015. <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>.

⁹ Association on Aging in New York. Fact Sheet, 2015. <http://www.agingny.org/Portals/13/Fact%20Sheets/Fact%20Sheets%202014/03-CaregiversJune2015%20-%202.pdf>.

- Supplemental Services are offered on a limited basis to complement the care provided by caregivers which may include, assistive technology, home modifications, incontinent supplies, legal assistance, or transportation.

Lifespan Respite Grant

The Lifespan Respite Grant initiative is a coordinated system of accessible, community-based respite services and other caregiver supports for family caregivers. The initiative brings together federal, state, and local resources and funding streams to help support, expand, and streamline the availability of respite services while providing for the recruitment and training of respite workers, and other caregiver supports and services. The New York State Office for the Aging (NYSOFA), NY Connects, Monroe County Office for the Aging (MCOFA), Lifespan of Greater Rochester (Lifespan) and the New York State Caregiving and Respite Coalition (NYSCRC) worked in partnership as a Lifespan Respite Core Team.

The goal of the Lifespan Respite Grant is to continue to build upon prior and current Lifespan Respite initiatives by engaging key stakeholders to increase and expand access to respite services statewide. As well as to enhance partnerships for education, outreach, and service provision to advance development of a Lifespan Respite Care System. Accomplishments associated with the Lifespan Respite Grant include:

- Developing a formal caregiver-directed respite services model using funds under the Older Americans Act (OAA) Title III-E (III-E) program, also known as the National Family Caregiver Supports Program. This optional model is being developed for use by Area Agencies on Aging (AAAs) that choose to adopt it and will offer greater flexibility with a person-centered approach for caregivers to identify and help address their respite needs. 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 the Retired and Senior Volunteer Programs (RSVPs) in targeted geographic areas to further expand the nationally recognized, evidence supported Respite Education and Support Tools (REST) model across the State.
- Monthly Webinars are provided to caregiver coordinators on various topics related to caregiving and respite for AAAs under OAA III-E.
 - More than 60 attendees participate each month. The calls are held as webinars or conference calls, based on the topic and presenter, each call is recorded and a link to access the recording is shared with invitees.

New York State Caregiving and Respite Coalition (NYSCRC)

The New York State Caregiving and Respite Coalition, NYSCRC, is a partnership of dedicated organizations and individuals committed to supporting the millions of New York State's family caregivers. NYSCRC members understand the unique needs of caregivers. Through training and education, NYSCRC focuses on increasing caregivers' access to respite resources and, through a unified voice gain the attention of policymakers for the needs of family caregivers.

With funding from the federal Lifespan Respite Grant and other sources, NYSCRC is training hundreds of volunteer respite providers throughout New York State. Greater availability to respite services will give caregivers more frequent breaks while helping them better manage the physical and emotional stresses that come with caring for an aging and/or disabled loved one.

NYSCRC takes an active role in improving the lives of informal caregivers, including:

- Supporting initiatives such as volunteer-based respite through mini-grants;
- Continuing to build its capacity and conduct outreach to the public;
- Distributing its Newsletter and/or updates at least monthly to an estimated 800 people and/or organizations;
- Raising awareness, educating, and increasing the NYSCRC identity through social media and blogging;
- Offering the Virtual Resource Center, a suite of evidence informed/evidence-based training services with an aim of further coordinating 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
- Reaching out to faith-based organizations through a collaborative team that have been working to identify strategies to promote supportive programs for caregivers through faith communities;
- Offering Respite Education and Support Tools (REST) training through 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). New York continues to be recognized nationally by REST for leadership and for rapidly expanding the evidence supported REST program, resulting in New York training the most REST trainers nationwide.
 - New York has built on the successes to date with recruiting and training additional REST Companions, who are volunteers.
 - NYSCRC implemented a new online reporting portal to track respite hours provided by REST Companions.
- StoryGrowing: The StoryGrowing concept is based on the teachings of Andy Goodman of The Goodman Center and is a nine-month training program that included lectures, workshops, private coaching, guided development, and presentation opportunities, all designed to meet the specific learning objectives. NYSCRC was one of eight chosen out of 50 applicants to participate in the StoryGrowing Initiative of Western New York.

- Lifespan Respite Sustainability Summit: On October 18, 2018, invitees with expertise and interest in caregiving and respite convened in Albany for the first Lifespan Respite Sustainability Summit. Participants included representatives from aging and disability networks across the State, ARCH National Respite, the Lifespan Respite core team (Lifespan/New York State Caregiving and Respite Coalition, NYSOFA, and Monroe County Offices for the Aging), New York State Agencies, local government, and caregivers. The objectives for the event were to:
 - Identify state-level policy and program needs and goals related to respite care services for children, adults, and aging population.
 - Strengthen State and community partnerships to sustain Lifespan Respite activities.
 - Develop strategies to maximize use of existing respite resources.

Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) is a federal law providing up to 12 weeks of unpaid, job protected leave in a single 12-month period to care for medical situations, including caring for an immediate family member. An employee must have worked for their employer for at least 12 months and have worked at least 1,250 hours over a 12 month period. Under FMLA, immediate family is considered a spouse, child, or parent.

State

New York State Paid Family Leave

New York State passed the Paid Family Leave Law on April 4, 2016, the most inclusive paid family leave in the United States. Funded through an employee payroll contribution that sets each year to match the cost of coverage, it pays eligible workers a portion of their salary while on leave from employment to care for a loved one. In effect since January 2018, Paid Family Leave expands on the federal act definition of “family member” to include domestic partner, stepchild, a son or daughter of a domestic partner or anyone a person has legal custody of, stepparent, parent-in-law, grandparent, or grandchild. Once fully implemented in 2021, employees will be able to take up to 12 weeks in a 52-week period and receive up to a statutory cap of 67 percent of their average weekly wage. Paid Family Leave guarantees job protection, continued health insurance on the same terms the employee had while working, and protection from discrimination or retaliation for requesting or taking Paid Family Leave. The benefit can be utilized all at once or spread out throughout the year to allow flexibility for a workers’ needs in caring for their family member.

Paid Family Leave is offered so a worker can bond with a new child, care for a family member with a serious health condition or assist loved ones when a family member is deployed abroad on active military service. A serious health condition is an illness, injury, impairment, or physical or mental condition requiring inpatient care in a hospital, hospice, or inpatient/outpatient resident health facility or continuing treatment or supervision by a health care provider. In 2019, the definition of “serious health condition” was expanded to include organ and tissue donation.

NY Connects and Caregivers

NY Connects is New York State's "No Wrong Door" for accessing long term services and supports in the State. In partnership with the Department of Health, Office for People with Developmental Disabilities, Office of Mental Health, and Office of Alcoholism and Substance Abuse Services, NY Connects serves individuals of all ages and disability groups seeking assistance with learning about and accessing long term services and supports, regardless of payor source. NY Connects is federally recognized as New York's Aging and Disability Resource Center (ADRC) and is an essential component of the State's efforts to rebalance the long term services and supports (LTSS) system so that older adults and people with disabilities of all ages can live independently and remain in their homes and community.

Caregiver Resource Centers (CRC)

Section 206 of the New York State Elder Law, Article II, Title I established the Caregiver Assistance Program within the New York State Office for the Aging. Under this program, the State Office for the Aging is authorized to establish training and assistance programs for caregivers of frail and disabled persons. Services that have been provided include group training/workshops, support groups, counseling/information, and Referral services.

Annual Regional Caregiver Forums

During May 2018, NYSOFA, the New York State Caregiving and Respite Coalition (NYSCRC), and the New York State Kinship Navigator partnered to facilitate Regional Caregiver Forums, titled "Caregiving and Respite Across the Lifespan: Linkages and Partnerships." The intended audience for the forums included Area Agency on Aging (AAA) leadership, staff, and subcontractor staff involved in assisting caregivers, staff providing NY Connects services, as well as those in the KinCare Coalition Network. The invitation to the forums was also extended to NY Connects staff from Independent Living Centers under contract with NYSOFA, Local Caregiver Coalition Members, and New York State KinCare Coalition members.

The day-long event was broken into two parts. The first segment offered an in-depth training review and discussion about resources to support caregiving and respite services needs in the aging network. For caregivers caring for individuals across the age and disability spectrum, the NY Connects systems reform initiative was presented, as well as the Kinship Navigator and its programs and services. The afternoon listening sessions were open to family caregivers. Participants with caregiving experience shared their story and offered recommendations on ways to address gaps and reduce barriers to accessing services and supports for New York caregivers.

State Respite Program

The State-funded respite program awards over \$1 million annually via grant awards to ten programs across the State to provide respite to caregivers of any age who provide support to older adults. In addition, many of these programs also provide other supports to caregivers, such as case management, counseling, support groups/training and information and assistance. In SFY 2017-18, ten agencies received a total of 13 grants.

CARE Act

The New York State CARE (Caregiver Advise, Record and Enable) Act went into effect on April 23, 2016. The CARE Act was created to ensure that hospital patients are afforded the opportunity and right to appoint a caregiver to be recorded in their medical chart during their hospital stay. Once appointed, the caregiver must be contacted and included to discuss the patient's plan of care prior to discharge or transfer. In addition, hospitals must offer training to the caregiver in tasks required post discharge.

Alzheimer's Disease Caregiver Programs

New York State offers extensive support to caregivers of individuals with Alzheimer's Disease or other dementias through the Alzheimer's Disease Caregiver Support Initiative. The programs that are under the initiative support caregivers and family members by offering the following:

- 24-hour helpline offering information and referrals;
- Care planning and consultation;
- Education and training for caregivers;
- Caregiver support groups;
- Respite; and,
- Caregiver wellness programs.

In addition to offering direct caregiver support, the initiative includes community awareness, outreach, and support and training for health care providers and health care students. Since the launch of the initiative in 2015 it has reached caregivers in every county, increased training of providers and students by 56 percent and increased diagnostic assessments by 75 percent.

Innovative Family Caregiving Supports

Understanding the needs of and addressing the roles family caregivers play in long term care is a key element of a high-performing Long Term Supports and Services (LTSS) system. With the critical role that family caregivers play in enabling their loved ones to remain in their communities or the setting of their choice, there is a value to ensuring family caregivers receive the necessary help to keep the cost of care sustainable and make it possible to access supportive services to prevent them from burning out.

Currently, there is more that can be done in recognizing and supporting family caregivers by advancing person- and family-centered care in the State to ensure that family caregivers do not experience burnout, quit their jobs in order to provide care, or compromise their own health and economic security. The following are a sample of innovative programs and policies employed by states and community-based organizations across the country that are demonstrative of how New York could better support their family caregivers.

Kupuna Caregiver Program

In 2018, Hawaii established the Kupuna Caregiver Program, a program focused on assisting employed family caregivers by easing the financial difficulties of providing care for those they care for and allowing them to continue working. Caregivers that participate in this program are eligible to receive up to \$70 per day to cover the cost of services associated with caregiving.

Costs may include adult day health care, chore services, transportation assistance, meal preparation, and caregiving counseling.

Caregiving 2031

Caregiving 2031, a model supported through the Robert Wood Johnson Foundation, is an innovative model that acknowledges the oncoming shortage of caregivers and looks to support the informal care support system to ensure that older adults can continue to be cared for outside of the institutional setting. This model recognizes that there is not a single solution to addressing the shortage of caregiving, but looks to redefine social norms, harness technology, and create a collaborative bridge between the informal and formal caregiving systems to identify usable strategies to address the caregiver shortage.

TCARE

Tailored Caregiver Assessment and Referral (TCARE) is a care management protocol designed to support family members who are providing care to adults, of any age, with chronic or acute health conditions. TCARE is grounded in the Caregiver Identity Theory, which conceptualizes caregiving as a series of transitions that result from changes in the caregiving context and in personal norms that are grounded in familial roles and culture. A major tenet of the theory is that identity discrepancy, defined as a disparity between a caregiver's behavior and his or her identity standards, or personal norms, is a major source of caregiver stress. Identity discrepancy can be manifested in three domains of burden (objective burden, relationship burden, and stress burden) and in depression. TCARE is a triaging mechanism for identifying strategies and services to minimize identity discrepancy.

Archangels

ARCHANGELS is a nationwide effort that leverages the retail channel as a way to identify, thank, and support caregivers by connecting them to the caregiver infrastructure that already exists, but that most caregivers don't know about.

Their goal is to be the trusted resource in supporting caregivers and re-framing how caregivers are perceived and supported. ARCHANGELS work with retail locations and their employees to open up the conversation around caregiving with customers. For example, Walmart locations have employees who wear wings or pins with wings with the goal of customers asking about the wings. Once they do, employees explain the importance of caregivers and how they recognize that caregivers are everywhere. If that customer then brings up that they are a caregiver or know a caregiver, the employee will then thank them and give them a care sheet that has local or state caregiving resource contact information.