



New York State Office for the Aging (NYSOFA) Caregiver Initiatives

The New York State Office for the Aging (NYSOFA) has a strong commitment to providing and improving services and supports to informal caregivers from across the lifespan - caregivers of older people, relative caregivers and caregivers of children and adults with special needs. This is done via partnerships and collaborations with sister state agencies and other public and private organizations. NYSOFA administers caregiver services through our network of 59 county offices for the aging also known as area agencies on aging (AAAs) and administers some state-funded Social Adult Day and Respite Programs that assist caregivers. Numerous community and faith-based organizations also assist caregivers through other public and private funding, such as the NYS Office of Children and Family Services Kinship Navigator Program and The Brookdale Foundation.

NYSOFA's mission is to help older New Yorkers to be as independent as possible for as long as possible through advocacy, development and delivery of person-centered, consumer-oriented, and cost-effective policies, programs and services which support and empower the elderly and their families, in partnership with the network of public and private organizations which serve them.

Informal caregivers are an invaluable resource to their loved ones and to the United State's health care system because of the care they provide. This unpaid care saves billions of dollars in state and federal funds. In New York, there are an estimated 2.2 million family caregivers providing care at an estimated annual value of \$25 billion, nationally the economic value is estimated at \$375 billion (source: AARP Public Policy Institute, November 2008). An increasing body of evidence indicates that caregiving can take a major toll on the physical and mental health of the caregiver. Caregivers who experience stress and burden are more likely to give up their daily caregiving responsibilities and place their loved ones in institutions, a more costly option to both the family and scarce public resources. Thus, we must support and assist caregivers to help sustain them in their caregiving roles. The following are programs and initiatives that NYSOFA supports in order to increase awareness of caregiver issues and to ensure caregivers are better served.

Caregiver Assistance Program

Since the late 1980's, NYS has funded 17 AAA Caregiver Resource Centers (CRCs) to provide caregivers of older persons with information, assistance, counseling, support groups, and training. These programs established under Section 206 of the NYS Elder Law, Article II, Title I, provide a single focal point of access for informal caregivers. In SFY 2007-08, they trained 6,112 individuals, held 49 support groups for 708 individuals, counseled 4,030 individuals and provided 10,833 units of information and referral.

New York Elder Support Caregiver Program

With the advent of the federal Older Americans Act, Title III-E funding, in 2001, NYSOFA established the New York Elder Caregiver Support Program, which operates via our network of 59 AAAs. These agencies provide a variety of supports to caregivers of older persons

(60 years and older) and approximately half of the AAAs serve grandparents and other older relatives (55 years and older) who care for children. AAAs provide information, assistance, training, support groups, counseling, a wide variety of respite services, and supplemental services that complement the care of the caregiver. Most AAAs have information for caregivers on their websites; link to: <http://www.aging.state.ny.us/findhelp/lofa.htm>.

Regional Caregiver Centers for Excellence (RCCEs)

The NY State Fiscal Year (SFY) 2008-09 budget included an appropriation to fund Regional Caregiver Centers for Excellence (RCCE). The goal of the RCCEs is to bolster and strengthen the capacity of the AAA and community-based and faith-based caregiver programs across the state. This funding also includes a direct respite component.

NYSOFA Caregiver Survey

NYSOFA has completed a statewide caregiver survey that studied the impacts of AAA caregiver support programs and ways to improve the programs to better serve caregivers. Thirty AAAs were randomly selected to represent the local programs and 1,209 caregivers participated in the survey that was administrated by the Finger Lakes Geriatric Education Center (FLGEC). Preliminary results have been shared with the NYS Family Caregiver Council and with Caregiver Coordinators on a conference call. The final report will soon be available to all AAAs. This initiative allows us to document the impact and merit of NYSOFA/AAA caregiver support services and programs in assisting caregivers caring for their loved ones. (See the NYS Family Caregiver Council section for information on a survey of caregiver services.)

NYSOFA's Caregiver Consumer Education Materials (available on AAARIN)

- *Resources for Caregivers in New York State*, a tri-fold pamphlet that provides phone numbers and web sites for caregivers. It comes with two detachable, wallet-sized caregiver resource cards for easy access to contacts.
- *Caregiver Toolkit*, an eight page comprehensive compilation of information covering the multiple and diverse issues/needs that caregivers face each day.

NYSOFA's Website: www.aging.ny.gov

Caregiving Pages: <http://www.aging.ny.gov/Caregiving/Index.cfm>

NY Connects – Choices for LTC is NY's consumer-centered access to information and assistance for all individuals in need of long term care services. NY Connects continues to develop in each county of the state providing consumers across the lifespan with information and assistance in accessing and understanding long term care services. 29% of calls to NY Connects are from caregivers.

Kinship Caregiving

A growing number of grandparents and other older relatives find themselves caring for their grandchildren and other relative children because the parent(s) are unable to care for them due to a variety of reasons. In NY, according to the last Census, close to 400,000 children live with their grandparents. There are another 111,806 children living with other relatives. These caregivers have unique needs many of which are of a legal nature.

The 2006 Older Americans Act amendments lowered the age for which Title III-E programs can serve grandparents from 60 to 55.

In June 2008, NYSOFA conducted an online survey of AAAs to determine their level of involvement in kinship caregiving and their knowledge of the NYS Office of Children and Family Services (OCFS) kincare programs. Forty-three AAAs responded. Of those, 61% serve grandparents and other older relatives, 34% see an increase in requests for assistance from kinship caregivers, 63% are aware of OCFS regional programs, 53% coordinate with them and 71% are interested in kincare training.

NYSOFA collaborates with NYS OCFS to educate local programs and caregivers about resources available to kinship caregivers and we encourage local programs to partner and make referrals among each other. The NYS OCFS Kinship Program is an excellent source of information for kinship caregivers. **The Kinship Navigator** at www.nysnavigator.org is an on-line resource for professionals and consumers. It has information and referral on laws, legal rights, issues on custody and visitation, eligibility for benefits and entitlement programs, tax credits, respite care, other local services, and links to the Regional Kinship Programs. You can talk to a kinship specialist at their toll-free number at 1-877-454-6463.

AAAs and other community and faith-based programs can also partner with local Relatives as Parents Programs (RAPP), which are funded by The Brookdale Foundation. You can link to their website at: (<http://www.brookdalefoundation.org/>).

NYSOFA is a member of the **NYS Kincare Coalition**, which is sponsored by AARP and the NY Life Foundation. This 60-member coalition meets quarterly to discuss and advocate for kincare issues, policies and programs. AAAs may join this coalition and/or sign up to receive their e-newsletter by contacting: LPolakoff@aarp.org. The *Kincare News* is a monthly e-newsletter produced by AARP New York on behalf of the NYS Kincare Coalition for professionals working in the kin caregiving field.

Kinship Care In NY: A Five-Year Framework for Action, 2008 Report, NYS Kincare Coalition, April 2008 details the recommendations of the November 2007 Kincare Summit held in Albany. The report's 19 recommendations focus on supporting the strengths of kinship families. Some of the recommendations mirror those of the NYS Family Caregiver Council. You can find the report online at: <http://www.nysnavigator.org/sf/providers.php>.

The June 2009 ACUU Conference will include a kincare workshop to complement last year's workshop, "Kinship Care: Today & Tomorrow." The workshop will be conducted by our partners NYS OCFS and legal expert Gerard Wallace, Esq. and will cover partnerships and 'connectivity', recent legislative and policy changes impacting kinship caregivers including the Fostering Connections to Success and Improving Adoptions Act.

New York State Family Caregiver Council

In 2007, the Governor designated NYSOFA as the lead state agency to establish and coordinate the work of the NYS Family Caregiver Council. NYSOFA coordinates the work of the Council with other state agencies that serve caregivers across the lifespan. Council members come from all regions of the state with a majority of them active family caregivers.

The Council's goals are to provide a strong statement of support for family caregivers; conduct a comprehensive mapping and evaluation of existing services and family caregiver needs; review key policies; establish a mechanism to coordinate these activities and propose new and expanded services and policy implementation; and focus on strengthening local agencies to reach, assess, and support caregivers. Council recommendations are presented to the Governor. The following are activities relating to the Council's 2007 recommendations, the results of which will be shared with State decision makers.

NYSOFA & NYS Family Caregiver Council Town Hall Meetings

In 2008, NYSOFA and the Council heard directly from caregivers from across the lifespan, service providers and advocates in caregiver town hall meetings. Town hall meetings have taken place in Dutchess, Rensselaer, Suffolk, St. Lawrence and Washington counties and with the NYS Assembly Puerto Rican/Hispanic Task Force and Senior Issues Committee of the Statewide LGBT Health & Human Services Network. Participant comments, including those from grandparent caregivers, clearly demonstrated that local caregiving and kinship programs have a positive impact on the lives of caregivers and their loved ones and that continued support to caregivers is vital. Input from these meetings assists the Council and NYSOFA in their work to serve caregivers. More town halls will take place in 2009.

NYS Caregivers Services Survey

NYSOFA contracted with the Finger Lakes Geriatric Education Center to conduct a system-wide assessment, sponsored by the NYS Family Caregiver Council, of caregiver support services through the existing Long Term Care Councils established for NY Connects: *Choices for Long Term Care* along with other key informants. The purpose of the assessment was to collect information on the availability and adequacy of local caregiver services so that a gaps analysis/needs assessment may be performed by the Council.

Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias Community Forums

Similar to the caregiver town hall meetings, the NYS Department of Health, in cooperation with NYSOFA, held a series of forums in 2008 to solicit input from professionals, caregivers and people with Alzheimer's disease on the concerns and challenges faced by people with Alzheimer's disease and their caregivers. The input will help them develop a NYS Comprehensive Plan on Alzheimer's disease and Other Dementias. Forums were held in Rochester, Brentwood, Queensbury, Binghamton, NYC, Cheektowaga and Syracuse. Similar themes were expressed at the town hall meetings and Alzheimer's Forums.

Statewide Caregiving and Respite Consortium of New York

This newly forming statewide cross-disability, intergenerational caregiving and respite consortium will serve as a platform and unified presence in New York to promote caregiver issues and programs for caregivers across the lifespan. A Lifespan Respite Summit to be held on May 19, 2009 in Albany will bring together key stakeholders from across the state to help shape the direction of New York's future lifespan respite program. Go to the National Respite Coalition's website at: <http://chtop.org/ARCH/ARCH-National-Respite-Coalition.html> to find out information on the National Respite Care Act and what other states are doing.