

# New York State Family Caregiver Council Report



**Supporting and Strengthening  
Caregivers in New York State  
2009**

*“You Care for Them, We Care For You”*

November 2009

Dear Director Burgess:

On behalf of the New York State Family Caregiver Council, we are submitting for your review and consideration the Report of the Council, *Supporting and Strengthening Caregivers in New York State*. The Council is comprised of a diverse representation of caregivers, including spouses/partners, adult children, parents of children with special health needs, family friends, faith group members, and grandparents and other relatives caring for children. These caregiver representatives make up a majority of the Council.

The New York State Office for the Aging and other ex officio members of the Council including the New York State Department of Health, Office of Children and Family Services, Office of Mental Health, Office of Mental Retardation and Developmental Disabilities, State Education Department, Office of Temporary and Disability Assistance, Department of Labor, Commission on Quality of Care and Advocacy for Persons with Disabilities, Office of Alcoholism and Substance Abuse Services, and the Developmental Disabilities Planning Council regularly participated in Council meetings. Various state agencies provided technical assistance in the preparation of this Report.

The Council met for the first time in the fall of 2007 and developed preliminary recommendations aimed at improving services to caregivers of all ages in New York State as the basis for action during 2008. In 2008, the Council focused its efforts on better understanding caregiver issues through a series of Town Hall Meetings throughout the state, and on evaluating programs and policies that affect caregivers and those they are caring for. This Report outlines those efforts and other actions taken during 2008-2009, provides information about informal caregiving and the issues and challenges this population faces, and provides recommendations for consideration. Our aim with this Report is to help deepen and broaden the understanding of informal caregiving and its impacts on families, communities, and New York State as a whole so that we may support caregivers in their vital role.

Thank you for your consideration of the information and recommendations included in this Report. We look forward to continuing our work in the coming year.

Sincerely,

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### **Family Caregiver Council Members**

The New York State Family Caregiver Council is comprised of caregivers of all ages who provide informal care to individuals across the lifespan who need such care, community advocates, academic experts in caregiving issues, and ex officio state government agency representatives.

- Renee Benson, Albany
- Geri Brooks, White Plains
- Pamela Canham, Albion
- Linda Campbell, Syracuse
- Brigitte Castellano, Vice Chair, Wading River
- Robert Coye, Syracuse
- Robin Fenley, Staten Island
- Morton Flexer, Westfield
- Cynthia Fountain, Chair, Newburgh
- Rose Golden, Delmar
- Linda James, Rochester
- Igal Jellinek, Manhattan
- Carol Levine, Manhattan
- Janet Long, Watertown
- Tracy Luo, Manhattan
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- Louis Nasca, Hornell
- Maggie Ornstein, Queens
- MaryAnn Pula, Cheektowaga
- Grace Rascoe, Plattsburgh
- Delilah Reyes, Rensselaer
- Sharon Shapiro, Brooklyn
- Catherine Thurston, Brooklyn
- Ronald Toseland, Selkirk
- Lois Wilson, Glenmont
- Betti Weimersheimer, Mamaroneck

The New York State Office for the Aging is the lead agency that coordinates the work of the Council. Staff support was provided in the preparation of this Report. The Council includes ex officio members from the following state agencies:

- Department of Health
- Office of Mental Health
- Developmental Disabilities Planning Council
- Office of Children and Family Services
- Office of Mental Retardation and Developmental Disabilities
- Office of Temporary and Disability Assistance
- Department of Labor
- Office of Alcoholism and Substance Abuse Services
- Commission on Quality of Care and Advocacy for Persons with Disabilities
- State Education Department - Vocational and Educational Services for Individuals with Disabilities

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# Executive Summary

## Introduction and Background

In New York State, it is estimated that at least 80 percent of community-based long-term care for persons of all ages is provided by family or other informal caregivers. This voluntary assistance reduces public spending for long-term care supports and services and has an estimated annual economic value of \$25 billion in New York State and an estimated national total of \$375 billion, which is more than the total Medicaid expenditures for nursing home and home and community-based services combined (*Houser & Gibson*).

Recognizing the value of family and other informal caregivers to the independence of persons of all ages with disabilities and their level of need for support, the Governor and the Legislature established the New York State Family Caregiver Council (Council) in the 2007-08 state budget. The New York State Office for the Aging (NYSOFA) was designated as the lead agency to coordinate the work of the Council. The Council includes caregivers across the age and care spectrum, community advocates, academic experts in caregiving issues, and New York State government agencies. The Council's mission is to provide guidance, advice, and recommendations that will enable the state to develop policies and programs that support caregiving by reducing barriers and enhancing support for individuals who provide care for friends, family, or community members of all ages and all levels of ability.

In its first year, the Council developed preliminary recommendations for action, which formed the basis for activities to support informal caregivers that took place during 2008. The recommendations were further refined and additional recommendations were identified by the Council in its second year. The recommendations for both years have been merged and will continue to inform the work of the Council in 2009 and beyond. These recommendations are summarized in this Report and included in full in Appendix A of this Report.

## Family Caregiving Information Gathering and Data Review

During 2008, the Council undertook multiple efforts to gather data and information about caregiving which included:

- **Town Hall Meetings**  
The Council sponsored seven Town Hall Meetings in 2008 to hear directly from caregivers across the lifespan. The information gathered was shared and discussed by Council members and included in the formulation of the recommendations listed in Appendix A of this Report.
- **The Alzheimer's Coordinating Council Community Forums**  
The New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (the Alzheimer's Coordinating Council) was established to: (1) facilitate interagency planning and policy review regarding

specific agency initiatives for their impact on care of persons with dementia and their families, and (2) provide a continuing forum for concerns and discussions on the development of state policy related to dementias and services for persons with dementia. The Alzheimer's Coordinating Council focused attention on caregiver-related efforts for persons with dementia, which is consistent with, and dovetails with, the work of the Family Caregiver Council. The Alzheimer's Coordinating Council held forums in the spring 2008 to gather information to be used in developing the Alzheimer's Coordinating Council Plan for 2009. A summary of information gathered at those public events and some of the personal stories of caregivers that were shared at those meetings are included in this Report.

- **Surveys:** The Council sponsored and took an active role in assisting the Finger Lakes Geriatric Education Center (FLGEC) in developing a survey designed to assess New York State caregiver services, identify ways to be more responsive to the needs of caregivers across New York State, identify gaps, and capture perspectives about caregiver services from each community's stakeholders (providers and consumers). Also in 2008, the NYSOFA undertook a statewide survey to: (1) gather detailed information that describes the population of caregivers who are served by NYSOFA/Area Agencies on Aging (AAA) caregiver programs and services, (2) quantify the impacts of NYSOFA/AAA support services and programs, and (3) help inform the program administrators, service providers, and policy makers in order to improve programs and services to become more relevant, beneficial, and efficient. The Council reviewed the findings from both surveys, and summaries of findings from each of those surveys and links to the survey reports can be found in this Report.

The Council is committed to working diligently to support caregivers in New York State. As part of that work, this Report was developed to summarize activities undertaken under the auspices of the Council in 2008 and 2009, highlight the value of caregivers, provide information on informal caregiver needs, and submit recommendations to enhance support for caregivers across the lifespan.

## Highlights of Family Caregiver Council Recommendations

*The Family Caregiver Council Recommendations are highlighted below and included in full in Appendix A.*

### 1. Strengthen Services and Programs that Support Caregivers and Care Recipients

- Identify and streamline funding sources for consumer-directed respite and address policy and/or regulatory barriers that inhibit providing respite across the lifespan.
- Support the development of a patient health care navigator program to pair trained volunteers with patients during discharge planning and short-term post-hospital needs.
- Identify transportation and escort transportation services that are provided to caregivers or care receivers by local agencies such as aging, social services, health, veterans, and/or volunteer groups.
- Support the development of a survey to better understand and address the needs of young caregivers in New York.
- Strengthen services to caregivers across the lifespan.
- Develop Regional Caregiver Centers for Excellence.
- Continue funding for Office of Children and Family Services regional Kinship Caregiver Programs.

### 2. Increase Information and Outreach to Informal Caregivers Across the Lifespan

- Increase access to information about community supports and services and streamline assistance through **NY Connects**.
- Work closely with hospitals, clinics, and doctor's offices to promote awareness of **NY Connects** as a vehicle to provide information about caregiver services.
- Continue to hold community meetings, such as Town Hall Meetings, around the state to provide a forum for caregivers to share their experiences and discuss what types of services and supports would aid caregivers.
- Promote the theme, *You Care for Them, We Care For You*. The video message, developed in 2008 for the Family Caregiver Council, should be further developed into a Public Service Announcement and distributed widely.
- Educate elected officials about the economic value of informal caregiving to New York State and encourage them to strongly support family caregiver programs and services across the lifespan.
- Produce and widely disseminate Caregiver Toolkits that provide information to assist caregivers to plan for their caregiving role and responsibilities.

### 3. Encourage Civic Engagement/Community Empowerment to Support Informal Caregivers

- Promote volunteerism by engaging community groups to support family caregivers (e.g., assistance such as friendly visiting, shopping, calls).

- Identify and study outcomes of existing grass roots efforts such as volunteers providing transportation, food banks and other services in their communities.

#### **4. Continue the Development of State and Local Infrastructure for Caregiver Services and Supports**

- Develop a statewide caregiver consortium or coalition that will bring together state, county, and community-based organizations that serve caregivers across the lifespan to work together and share resources to better serve and educate their respective populations.
- Continue to work closely with state agencies acting as ex officio members of the Council to ensure that assessment tools assess the needs of the caregiver and the care receiver and recognize them as a family unit.

#### **5. Expand Training and Education for Informal and Professional Caregiving**

- Develop flexible person and caregiver-centered training/education (on-line, in-person and group settings). Specific topics could include addressing functional and emotional areas, and that training and education should be culturally relevant to caregiver(s).

#### **6. Educate and Involve Business and Workforce in Caregiving Issues**

- Provide additional support to caregivers by educating and involving employers and the workforce in creative solutions to allow caregivers to remain a productive part of the workforce.

#### **7. Improve the Rights of Caregivers**

- Assist caregivers dealing with barriers in the health care system.
- Explore possible options to strengthen the financial security of caregivers.

#### **8. Enhance Housing Options and Supports**

- Collaborate with the NYS Division of Housing and Community Renewal (DHCR) to establish a program to develop and evaluate affordable innovative housing alternatives that would enable caregivers to provide assistance to individuals so that they can remain in their community.
- Continue the Access to Home Program to fund adaptive use modifications in homes to assist caregivers in providing care and assistance to individuals that would otherwise be placed in a higher level of care.
- Support the ongoing efforts conducted under the Housing, Planning, and Zoning Initiative, which is being implemented jointly by NYSOFA and the New York State Department of State.
- Strengthen and promote NYSOFA housing-related programs designed to assist older adults to remain in their own homes and communities.

## Introduction and Background

### Who Are Informal Caregivers?

Informal caregiving refers to unpaid family members, friends, neighbors, and grandparents and other relatives who provide full or part time care to persons with disabilities or special care needs, and grandchildren. Informal caregiving helps preserve crucial kinship ties and provides an inestimable social and economic service to society (*Burnette*).<sup>1</sup>

*“Informal caregiving – often chosen, sometimes foisted upon an individual – is a vital part of our society. The services provided by the informal caregiver should be recognized and sustained. These individuals need the support of their family, friends, and community. Support – financial, emotional, hands-on, and educational – is necessary to ease caregiver strain and prevent caregiver burnout.”* (Glassey)

### National Profile of Informal Caregivers

Nationally, unpaid family caregivers provide the largest source of long-term care services in the United States. Nearly 7 million people (family, friends, and neighbors) provide care to persons aged 65 and older who need assistance with every day activities. The typical person most likely to be providing care to an older person is a 46-year-old female, who has some college education, works, and spends more than 20 hours a week providing care to her mother (*Gibson and Houser*). As care recipients age, there is a much higher likelihood of receiving care from a spouse. Nearly one-quarter (22 percent) of caregivers who are themselves 65 and older are caring for a spouse. Some studies have found that a significant percentage of caregivers (17 to 24 percent) are caring for a friend or neighbor as opposed to a family member (*Family Caregiver Alliance*). Nationwide, there are an estimated 1.3 to 1.4 million child caregivers between the ages of 8 and 18 years old. Of all households in the United States with a child 8 to 18 years old living there, 3.2 percent include a child caregiver (*National Alliance for Caregiving and United Hospital Fund*). There are between 3.9 and 5.2 million young adult caregivers (18 to 25 years old) in the United States (*Levine, Hunt, et.al*).

### National Facts and Figures: Caregivers of All Ages

In the United States (U.S.), 44.4 million caregivers aged 18 and older provide unpaid care to another adult who is 18 or older (21 percent of the adult U.S. population).

- Caregivers are present in an estimated 22.9 million households (21 percent of U.S. households).
- The average age of a caregiver is 46; 58 percent are between the ages of 18-49 years; 42 percent are 50 years of age or older. Minority caregivers are more likely to be 18-34 years old than white caregivers.
- 61 percent are women; 39 percent are men.
- Younger caregivers tend to care for younger care recipients.

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<sup>1</sup> Publications referenced in this Report are cited in full at the end of the Report.

- 59 percent work either full or part-time while providing care; 66 percent of male caregivers work full or part-time; 55 percent of female caregivers work full or part-time
- On average, caregivers provide 21 hours of care per week; 17 percent provide more than 40 hours of care per week; and the average length of care is 4.3 years.
- Female caregivers provide more hours of care and a higher level of care than male caregivers.
- 40 percent of female caregivers report experiencing emotional stress as a result of caregiving, and 26 percent of male caregivers report experiencing such stress.
- 42 percent of female caregivers and 34 percent of male caregivers reported they did not have a choice in becoming a caregiver.
- Older family caregivers experiencing strain are 63 percent more likely to die than their non-caregiving peers.

### **New York State Profile of Informal Caregivers**

New York State, with more than 2.2 million caregivers, ranks third in the nation in number of informal caregivers. Caregiver arrangements exist in approximately 734,000 New York State households, or one in ten of all New York State households. An estimated 2.2 million adults are providing over 2 billion hours of special care to family members with significant needs for assistance in New York State (*Family Caregiver Alliance*). In addition, there are 297,239 children living in grandparent-headed households in New York, or about 6.3 percent of all the children in the state, and there are 111,806 children living in households headed by other relatives. Of the children living in households headed by grandparents or other relatives in New York, 165,493 are living there without either parent present and 143,014 grandparents report they are responsible for their grandchildren living with them (*AARP, 2005*).

### **New York State Facts and Figures: Aging Services Network**

In 2008, the New York State Office for the Aging (NYSOFA) conducted a Caregiver Support Programs Participants Survey (NYSOFA, 2009), the results of which underscore the importance of caregivers and their roles in the lives of older adults in the State's communities:

- The typical caregiver in the New York aging services system is a 64-year-old female, who has either high school or some college education, and spends more than 40 hours a week providing care to her mother.
- Most (66 percent) caregivers are married and close to one fifth of the population reported household incomes below \$20,000.
- Individuals receiving care are more likely to be female (64 percent) and a majority (85 percent) are ages 75 or older.
- Many care receivers have significant health needs, with 94 percent of the caregivers reporting that their care receivers had at least one health problem. The most prevalent health condition of care receivers was Alzheimer's disease or other dementia: 75 percent reported this condition. Care receivers also have many functional limitations.
- The majority (85 percent) of care receivers have one or more impairments in taking a bath or shower, walking, dressing, getting in or out of a bed or chair, getting around inside the home, using the toilet, and eating. Further, 79 percent of individuals receiving care have three or more activities of daily living limitations as reported by the caregivers.

- Caregivers served in New York caregiver support programs report spending an average of 62.6 hours a week providing care, which is considerably higher than the national average of more than 20 hours estimated in a recent AARP report (2008).
- The care and assistance that caregivers provided ranged from 24 hours a day care or supervision to assisting in specific tasks, such as: transportation (96 percent), financial management (85 percent), arranging for care or services (86 percent), housekeeping (86 percent), arranging for home repair (82 percent), helping with medical needs (79 percent), performing home repair (77 percent), personal care (68 percent), and paying for services (68 percent).
- Caregivers participating in New York caregiver support programs tend to have a heavy care load: 36 percent reported that their care receivers cannot be left alone at home, and 42 percent reported that their care receivers can only be left alone for short periods of time or need to be checked on in person several times a day.

### **Economic Value of Informal Caregiving**

It is estimated that at least 80 percent of community-based long-term care is provided by family or other informal caregivers. This voluntary assistance reduces public spending for long-term care supports and services, and has an estimated annual economic value of \$25 billion in New York State out of an estimated national total of \$375 billion, which is more than the total Medicaid expenditures for nursing home and home and community-based services combined (*Houser & Gibson*). Informal caregivers perform numerous activities to assist care recipients to live at home in the community. These caregiving activities range from providing 24 hours-a-day assistance or supervision, to assisting in daily tasks such as transportation, housekeeping, personal care, and financial management.

### **Employment Status**

Most caregivers are employed; nearly six in ten caregivers (59 percent) either work or have worked while providing elder care to family members. Between 25 and 35 percent of all workers report that they are currently providing or have recently provided care to someone aged 65 and older. (*Family Caregiver Alliance*).

<i><b>Employment Status</b></i>	<i><b>% of All Caregivers</b></i>
Employed full-time	48%
Employed part-time	11%
Retired	16%
Not employed	9%

### **Workplace Impacts**

With over 44.4 million Americans providing care to another adult, the impact on the workplace is substantial. The losses to the economy when they leave, lose their jobs or fail to work to their full productivity are significant. Nationally, losses are estimated to cost businesses \$33.6 billion a year due to employees' need to provide care to people aged 50 and older (*MetLife Mature Market Institute and National Alliance for Caregiving*). Working caregivers often suffer work-

related difficulties due to their dual caregiving roles. Among working caregivers caring for a family or friend aged 65 and older, two-thirds report having to rearrange their work schedule, decrease their hours, or take an unpaid leave in order to meet their caregiving responsibilities (*Family Caregiver Alliance*).

About 62 percent of caregivers report having had to make some work-related adjustments to fulfill their caregiving responsibilities. More than half of working caregivers (57 percent) say they have to go into work late, leave early, or take time off during the day to provide care. Working caregivers report having to take a leave of absence (17 percent), go from full-time to part-time work (10 percent), quit working entirely (6 percent), lose job benefits (5 percent), turn down a promotion (4 percent), or choose early retirement (3 percent).

The MetLife Mature Market Institute reports the following estimated costs to employers:

- \$2.8 billion to replace employees who leave the work place for caregiver responsibilities;
- \$3.4 billion for absenteeism due to caregiving;
- \$2.8 billion for workday interruptions due to caregiving responsibilities,
- \$825 million for partial absenteeism due to caregiving responsibilities;
- \$1.6 billion for unplanned time away from work due to a caregiving crisis (1997 data);
- \$1.4 billion for unpaid leave due to caregiving responsibilities; and
- \$3.4 billion for reducing hours from full-time to part-time due to caregiving responsibilities.

## **New York State Family Caregiver Council**

### **Background and Purpose**

Recognizing the value of family and other informal caregivers to the independence of persons of all ages with disabilities, the Governor and the Legislature established the New York State Family Caregiver Council in the 2007-08 state budget. NYSOFA was designated as the lead agency to coordinate the work of the Council. The Council includes caregivers across the age and care spectrum, community advocates, academic experts in caregiving issues and New York State government agencies. The Council's mission is to provide guidance, advice, and recommendations that will enable the state to develop policies and programs that support caregiving by reducing barriers and enhancing support for individuals who provide care for friends, family or community members of all ages and all levels of ability.

### **First-Year Accomplishments of the Family Caregiver Council**

In its first year, the Council recommended strategies for action, which formed the basis for activities to support informal caregivers that took place during 2008 and 2009. These activities are summarized below:

- **Strengthen Community Support Services for Caregivers:** The Council identified the need for more support services for caregivers, including a statewide network of local Caregiver Resource Centers that provide and coordinate a range of services including

respite care; counseling and support groups; transportation; care coordination and advocacy; and training for caregivers.

**Action Steps:** The Executive Budget for State Fiscal Year 2009-10 included a reappropriation of the SFY 2008-09 funds for Regional Caregiver Centers for Excellence (RCCE). The RCCEs are intended to strengthen the capacity of the Area Agencies on Aging (AAAs) and community and faith-based caregiver support programs across the state so they may better serve New York's caregivers.

- **Increase Information and Outreach:** The Council identified the need to increase access to streamlined information and assistance about community supports and services through **NY Connects: Choices for Long Term Care**.

**Action Steps:** Funding was included in the 2008-09 budget to continue **NY Connects** as a vehicle to provide objective information about the array of options available in communities to support consumers, caregivers and professionals. The Council also identified the need to reach out to caregivers, particularly those who do not self-identify as caregivers. Subsequently, the Council has been working with NYSOFA staff to develop a media campaign that will reach out to all caregivers to help them to recognize their valuable role as a caregiver and provide information on how to obtain support should they need it.

- **Enhance Housing Options and Supports:** The Council identified housing for loved ones as a major concern of caregivers.

**Action Steps:** The New York State Conference, *Empowering Communities for Successful Aging*, held in November 2008, provided a forum to discuss housing, neighborhood supports and services, and provided communities with tools to become elder friendly and more livable for persons of all ages. In addition, NYSOFA and many of the ex officio members of the Council are active participants in the Most Integrated Setting Coordinating Council (MISCC), which is responsible for developing a comprehensive statewide plan to assist people of all ages with physical and mental disabilities in accessing care and services in the most integrated settings appropriate to their individual needs. Housing is a primary focus of the MISCC's work.

- **Improve the Rights of Caregivers:** The Council identified the need for caregivers to understand their rights when assisting their loved one with legal or medical issues.

**Action Steps:** A Caregiver Tool Kit and Wallet Card were designed to assist caregivers to better know their rights and where to call for assistance. This information has been widely distributed at meetings, events and to the local AAAs.

- **Continue to Develop a State and Local Infrastructure:** The Council identified the need for better communication about caregiving issues and strategies, and affirmed the value and need to continue its work.

**Action Steps:** Quarterly meetings of the Council were held with the continued participation of ex officio state agency representatives. Linkages were formed with the Alzheimer's Coordinating Care Council, and with the New York State KinCare Coalition. The development work for a statewide caregiver and respite coalition was undertaken.

These action steps are consistent with Governor Paterson's agenda to support New York State families and with NYSOFA's continuing efforts to advance community-centered, family-centered, caregiver-centered, and customer-centered approaches to meeting the needs of older adults and caregivers for persons of all ages. The Council's activities during its first year:

- recognized the importance of caregivers and community-based care and support services;
- incorporated cultural, linguistic, age-related, sexual orientation, and disability competencies, as well as the MISCC's General Principles and Guidelines;
- addressed caregivers caring for people across the lifespan; and
- recognized the interconnected relationships, program needs, and issues for the caregiver and care receiver.

## **Learning from Caregivers: Defining, Evaluating, and Identifying Program and Service Needs**

### **Town Hall Meetings 2008 and 2009: Overview and Summary**

Planned by NYSOFA and sponsored by the Council, eight Town Hall Meetings were held in 2008 and 2009. The purpose of the Town Hall Meetings is to meet with, share information, and hear directly from caregivers across the lifespan.

For the Town Hall Meetings, a panel consisting of Council members, NYSOFA executive staff, and local AAA Directors received comments and heard stories from caregivers about their experiences and ways in which they could be supported. The meetings were held at the following locations:

- Rensselaer County - February 8, 2008
- Washington County - April 23, 2008
- Dutchess County - April 24, 2008
- Somos El Futuro Conference – Albany - April 25, 2008
- Statewide Lesbian, Gay, Bisexual and Transgender (LGBT) Health and Human Services Network – Albany - April 28, 2008
- Suffolk County - May 23, 2008
- St. Lawrence County – June 13, 2008
- Orange County – November 9, 2009

The meetings were structured to encourage people to participate and testify about the following issues:

- What are the most critical needs you face as someone who provides care to a family member or other individual in the community?
- What assistance and supports are most critical to you, your family, and other informal caregivers who are assisting loved ones with everyday tasks in their homes and communities?
- What barriers do you face as a family caregiver? What makes it hard for you to provide care?
- What innovations are needed to support caregivers?
- Are there “best practices” that can be shared with others?

The testimony from speakers at each meeting was compelling and served as a valuable resource to the Council as it began to draft recommendations for 2008 and 2009. Input from caregivers at the Town Hall Meetings framed the many challenges and rewards of providing care to a loved one and also included information to help develop future policies about services that help and support caregivers. A full report from the Town Hall Meetings is included in Appendix B. Samples of experiences shared by caregivers at Town Hall Meetings are also included later in this Report.

### **Family Caregiving: Information Gathering and Data Review**

The Council has been both guided and benefited from work that was undertaken to collect information about caregivers and caregiving issues in New York State. As part of this effort, two major caregiver studies were designed and implemented: (1) the “New York State Caregiver Services Survey: **NY Connects** Local Long Term Care Councils’ Assessment of Caregiver Support Services” was a direct outgrowth of Council activity and was designed to survey key informants about caregiver services in order to quantify both gaps in services and policy barriers for programs providing support across the age span; and (2) the New York State Office for the Aging and Area Agencies on Aging’s “Caregiver Support Programs Participants Survey” was designed specifically to study the impacts of caregiver programs offered through NYSOFA and the AAAs and ways to improve those programs in order to better serve New York’s caregivers of older adults. The reports from these surveys were valuable to the Council in providing information about caregivers who are providing care and support to older adult care recipients.

The Council also reviewed information gathered from the Community Forums conducted by the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (Alzheimer’s Coordinating Council), and the *Kinship Care in New York* report from the New York State KinCare Coalition.

Each of these activities is highlighted below.

#### **New York State Caregiver Services Survey**

The “New York State Caregiver Services Survey: **NY Connects** Local Long Term Care Councils’ Assessment of Community Caregiver Support Services” was developed and implemented in the summer of 2008 by the Finger Lakes Geriatric Education Center (FLGEC) at the University of Rochester, in conjunction with NYSOFA, to assess New York State caregiver services and identify ways to be more responsive to the needs of caregivers across New York State. The objective of the survey was to collect information from ‘key informants’ about their knowledge regarding available services to caregivers locally in order to identify gaps in local community services for caregivers and to capture perspectives that are representative of each community’s stakeholders (providers and consumers).

The survey provided a useful perspective on caregiver services as reported through a “key informant” model of evaluation and research. The survey sample included a diverse group of key informant survey respondents through a representative sample of local Long Term Care

Council members from across the state. Further, Council members identified caregivers in the community to participate in the survey. These local Councils have been established as an important component of the **NY Connects: Choices for Long Term Care** programs in the 55 participating counties. Among the local Long Term Care Council membership are caregivers, service providers, recipients of services in the respondent group and county government officials. Survey respondents were asked to identify the top areas that the State should address as relating to caregiver services. A total count and ranking of summary recommendations are provided in the table below.

<b>Rank</b>	<b>Recommendation Category</b>
1	Transportation/more transportation
2	Respite services/more respite
3	Better training/education for staff
4	Support/help for caregivers
5	Recruitment of staff/aides
6	Home care/in home services
7	Funding/adequate funding
8	Affordable/less expensive services
9	Social Adult Day Services/Adult Day Health Care
10	Better pay/higher salaries for staff
11	Funding for respite/more respite
12	Increased awareness/public awareness

The full report, *New York State Caregiver Services Survey: NY Connects Local Long Term Care Councils' Assessment of Community Caregiver Support Services*, is available on the NYSOFA website at <http://www.aging.ny.gov/Caregiving/Reports/Index.cfm>.

### **NYSOFA Caregiver Support Programs Participants Survey**

The New York State Office for the Aging and Area Agencies on Aging's "Caregiver Support Programs Participants Survey" was a statewide caregiver survey to study the impacts of caregiver support programs and ways to improve the programs in order to better serve caregivers of older adults (aged 60 and older) in New York. The Caregiver Support Programs Participants Survey was funded by the federal Administration on Aging (AoA), as part of the Performance Outcomes Measures Project (POMP) under AoA Grant# 90AM3103, to test a statewide survey methodology and to assess the outcomes of caregiver support programs administered through the aging services network in New York State.

A preliminary survey was conducted of the 59 AAAs. Subsequently, 30 AAAs were randomly selected in order to draw an appropriate sample representing the caregivers served by aging network caregiver support services. A total of 1,209 caregivers were randomly selected from participants of caregiver support programs for survey participation. The random selection criteria for caregivers for this survey were that the caregiver must be:

- at least 18 years of age;

- a family member, friend, or neighbor who helps care for an elderly individual (aged 60 or older) who lives at home; and
- receiving caregiver support program services during State Fiscal Year 2007.

The Caregiver Support Programs Participants Survey was developed by NYSOFA and administered by the FLGEC, with the survey data collection completed in July 2008.

Some of the key findings from this survey include:

- The typical caregiver in the New York aging services network is a 64-year-old female, who has either high school or some college education, and spends more than 40 hours a week providing care to her mother.
- The majority (60 percent) of the caregivers are older adults themselves. Their ages range from 32 to 94, with an average age of 64, and 30% are aged 75 or older.
- The average age of care receivers is 82.5 years old. Most (60 percent) care recipients are aged 75 or older and the oldest care receiver is aged 102.

The full *Sustaining Informal Caregivers: New York State Caregiver Support Programs Participants Survey: Report of Findings on the Aging Services Network* is available on the NYSOFA website at <http://www.aging.ny.gov/Caregiving/Reports/Index.cfm>.

### **New York State Coordinating Council for Services Related to Alzheimer's Disease Community Forums**

The New York State Coordinating Council for Services Related to Alzheimer's Disease (Alzheimer's Coordinating Council), chaired by the New York State Department of Health, was established to facilitate interagency planning and policy, review specific agency initiatives for their impact related to the care of persons with dementia and their families, and provide a continuing forum for concerns and discussion related to the formulation of state policy related to dementias and services for persons with dementia. The Alzheimer's Coordinating Council focused attention on caregiver-related efforts for persons with dementia, which is consistent with, and dovetails with, the work of the Family Caregiver Council.

Eight Community Forums were conducted in the spring of 2008 to hear testimony and to help inform the development of the *New York State Comprehensive Plan on Alzheimer's Disease and Other Dementia in the Community*, scheduled for release in 2009. Caregivers, individuals with Alzheimer's disease and other dementias, family members, health and social services providers, law enforcement officers, and other community members had the opportunity to share stories and experiences about caring for and providing services to this population.

### **Kinship Care in New York: A Five-Year Framework for Action**

In 2008, the New York State Kincare Coalition, a statewide network of organizations and agencies that are dedicated to empowering kinship caregivers, released its recommendations for a five-year plan of action to better support the grandparents and other relative caregivers who are

raising more than 400,000 children in New York State. Efforts of this group also dovetail with the work of the Family Caregiver Council, and the two groups are working to collaborate and exchange information relevant to each group.

The Kincare Coalition report, titled *Kinship Care in New York: A Five Year Framework*, puts forth a number of recommendations aimed at crafting laws and policies to adequately address the unique needs of grandparent caregivers, who are the backbone of a growing informal caregiving population existing outside of the foster care system. By stepping in to care for their grandchildren when parents are unable to parent, these caregivers provide stability for children and keep them out of the formal foster care system.

The full *Kinship Care in New York Report* can be viewed and downloaded from the Kincare website at [http://www.nysnavigator.org/files/sf/2008\\_aarp\\_kincare\\_report.pdf](http://www.nysnavigator.org/files/sf/2008_aarp_kincare_report.pdf).

## Sharing the Voices of Caregivers

Hearing directly from caregivers offers a window into their realities – how their lives are affected by the care they provide and the rewards and the challenges of providing such care – and informs the consideration of how best to further develop supports that will assist caregivers in this vital role. The personal stories included below are both compelling and essential in guiding the work of the Family Caregiver Council. Included are several stories that were generously shared by members of the Council, a sampling of the stories told by informal caregivers at the 2008 Town Hall Meetings, and stories from caregivers attending the Alzheimer’s Coordinating Care Community Forums – told in their own words.

### Rewards and Challenges – Personal Stories from Family Caregiver Council Members

#### *Caregiving for Parents, With Love*

When my in-laws moved into our home, they were 87 and 88 years old and in reasonable health. Since we have a two story home and they could no longer traverse stairs, we changed our living room into a bedroom/sitting room. My father-in-law still drove, so they still had the independence to go out for breakfast in the mornings, as weather allowed. For two years all was well, and we spent wonderful hours cooking together (both of them were great cooks) and playing cards. At the end of two years, my mother-in-law began having health problems and needed personal care, which I was able to provide for her. We never employed outside help, as I was a female helping another female whom I loved.

**My mother-in-law began having health problems and needed personal care, which I was able to provide for her. I was a female helping another female whom I loved.**

Shortly thereafter, my father-in-law developed rectal cancer and needed personal care that I could not provide. The task of looking for an aide was daunting, and each new person that entered our home came with her or his own problems. We called agency upon agency to find someone reliable. There was no help on the county level and we were left on our own. We were able to keep my father-in-law at home where he died in his bed. A year after his death my mother-in-law fell and broke her arm. She went into the hospital and then into a nursing home for therapy. She was 91 and very frail, but possessed a fine mind.

Although the nursing home was decent, there were too many patients and not enough attention to each patient. I stood outside the bathroom door as some aides were giving my mother-in-law a shower. She cried for me to come into the bathroom and help her but I was not allowed. I could hear her screaming as she asked them to please watch out for her broken arm. They were chatting and laughing amongst each other, totally oblivious to her cries. We visited daily and one day I noticed she had a high fever. I had the attendant call the ambulance to take her to the hospital where she died a few weeks later. I believe the stay in the nursing home broke her spirit as well as her body. It is my regret that we did not insist on in-home therapy where she was comfortable and secure. We need to ensure that caregivers obtain the necessary help so loved

ones can remain in their homes to live and die with dignity. Nursing homes should be the very last resort, and their employees need to be trained to listen and respond to their patients.

### *Becoming a Teenage Caregiver*

I was 17 years old, a senior in high school with hopes of attending college away from home when my mother suffered a cerebral aneurysm rupture that left her in a coma for several months. Before I knew the extent of her injury, I remember thinking that she would be in the hospital for a little while before recovering and going back to work.

**I had no idea what was in store for my family or that I had instantly become a “young caregiver.” The incredible amount of responsibility thrust upon me was daunting.**

I had no idea what was in store for my family or that I had instantly become a “young caregiver.” The incredible amount of responsibility thrust upon me was daunting. My Mom was in three hospitals and a nursing home over a period of 6 years. Today, 12 years later, she is at home with my 98 year-old grandmother, and has beaten all of the odds. While the care they require changes with each illness and passing year, one thing remains reliable – the constancy and ongoing nature of the care and effort required to maintain them safely at home.

Being a family caregiver at any age is difficult. Being a young caregiver carries additional struggles as we work on our own personal growth and development while simultaneously caring for others who would typically be caring for us. At an age generally associated with becoming independent and separating from family, I became in charge of my mother’s life and near-death trauma. All the while, I had to find my own way with little professional help or recognition of my role in my mother’s and grandmother’s care.

### *A Grandmother’s Story*

In 1987 when my granddaughter was born, she weighed 1 lb. 4 oz. at birth. She was born in a drug house and later transported to a hospital in Maryland; because of her health, she was later transferred to Children’s Hospital in Washington, DC. I was notified by the hospital that my granddaughter needed surgery and that the hospital couldn’t find her mother. I gave consent for the surgery and asked the hospital to stay in contact with me because I would take responsibility for my granddaughter when it was time for her to be released (I knew that my daughter would not be located because she was back on the streets.) When the hospital notified me that she could be released, I had to find a way to bring her here to Rochester, NY. The dilemma I encountered was her medical conditions would not allow her to travel to Rochester on a regular airplane. She was hooked up with a heart monitor and breathing machine that would require a private plane with medical staff. After trying to connect with many agencies, I was finally able to find some assistance. A local radio station

**My story, like those of so many grandparents who are raising their grandchildren, began many years ago, most unexpectedly.**

arranged a flight to Washington, D.C. for me and also helped to arrange a Mercy flight (a medical flight with a nurse aboard) from Washington to Rochester.

This was a journey that would dramatically change my life. I was forced to quit my job at a local hospital in order to take care of my granddaughter and apply for assistance through our local Department of Human Services. Two years later, I was making that same journey to pick up her brother, who also was born premature. His weight was 1 lb. 6 oz.; my daughter at the time of his birth was still using drugs (my grandson was eventually diagnosed with ADHD and Auditory Processing Delay). In 1990, I was able to bring my daughter to Rochester hoping that the change would give her the desire to change her life style. For six months she stayed clean, but then she returned to her patterns of drug abuse. A year later, her body was found in an abandoned field; she was strangled two days before her 26<sup>th</sup> birthday. After the death of my daughter, I received counseling, along with my grandchildren, to help us deal with our loss and grief.

### *A Husband Cares for his Wife*

Six years ago, my wife, Norma, was diagnosed with dementia, and appropriate medications for treatment were started. Her first few years went reasonably well, with her being able to maintain a near normal life at home until memory loss and her ability to function normally required more care. Hospitalization and follow up physical therapy for a fractured shoulder further complicated her condition and upon return home, family and home aides were called to assist with her care.

As a caregiver, I managed her medications, prepared meals with the assistance of Meals on Wheels deliveries, managed the housework, provided transportation for appointments and social outings, and was with her as much as possible for companionship. For the last year at home she had home aides three days a week, including a full weekend day affording me welcome respite time. The local Office of Aging and Youth Expanded In-home Services for the Elderly Program provided financial assistance for the home aides and respite opportunities.

**For the last year at home she had home aides three days a week including a full weekend day affording me welcome respite time.**

Norma's condition worsened in September, 2007. After a brief hospitalization, she was admitted to a nursing home initially for rehabilitation; however, her Alzheimer's had progressed and it became just a matter of time before the end. With the exception of respite time, I spent as much time as possible with her, with daily visits to the nursing home. Her Living Will advising no further medical treatment was honored. Norma passed away peacefully Nov. 7, 2007.

## Individual Experiences Heard at Town Hall Meetings

### *A Wife's Difficult Decision*

My grown children have accepted the fact that their father has Alzheimer's Disease and spend time with him when they come to visit. Unfortunately, they both live quite a distance away. My husband has no close living family members and my family became our family. We were very close and spent holidays, birthdays, and many other days with them, even when there wasn't an occasion to celebrate. Now that my husband is in the middle stages of Alzheimer's Disease, my family seems to be uncomfortable spending time with him. I feel very sad and lonely. Because my family does not support my decision to keep my husband at home, I rely on my support group. Without them, I don't know what I would do.

**My family does not support my decision to keep my husband at home. Without my support group, I don't know what I would do.**

### *A Grandmother Asks for Help*

I am a 67-year-old grandparent raising my 13-year-old granddaughter because my daughter suffers from mental health issues. The increasing number of grandparents raising grandchildren is due to drug/alcohol abuse and mental health issues. Please put more funding into mental health issues and services to overcome drug and alcohol abuse.

**The increasing number of grandparents raising grandchildren is often due to drug/alcohol abuse and/or mental health issues of the parent.**

Grandparents need information and assistance to find support to assist them in their caregiving role. They also need respite services such as summer camp.

## Experiences Heard at Alzheimer's Council Forums

### *Choosing Caregiving Over Career*

I had a wonderful position. I was able to do a lot of work on the internet, keeping up with my day-to-day work, so my work never suffered. My clients loved me, but my company made it difficult. They told me that I was not to be taking vacation time or my personal time or even time off without pay because it sent a wrong message to the other employees. If they allowed me to take my mother to doctor's appointments, then anybody could take off at any time.

**I would like something to be done for people like myself, in the company that valued me only when I was the employee and when I became a caregiver I was nothing.**

Eventually the stress became too much, and I quit my job. My company said fine, no problem.

I had been there 14 years. I would like something to be done for people like myself, in the company that valued me only when I was the employee and when I became a caregiver I was nothing.

Over \$70,000 worth of pay and benefits went right out of our lives and my husband of four months was now supporting me and my mother. My husband is a saint. I am honored to be taking care of my mother. I wouldn't change anything.

### *Caring for an Aunt with Alzheimer's Disease*

The oldest of my three aunts who live together has Alzheimer's disease, and I am the only nephew. All the responsibility for taking care of these three ladies has fallen to me. I was woefully unprepared for the emotional, logistical, legal, and medical issues that came my way. When my aunt started to get what now I know is Alzheimer's disease, I didn't understand what was going on. Her personality started to change. I tried to get her into some of the local programs but I have my own life and family to deal with. My aunts don't live with me; they are fairly nearby, but not that close. I can't go over there every day to get them to day care. I have three kids of my own and a wife who works also. I have three people to care for, but a lot of my friends are also struggling just caring for one person. We need a better system. It is a heavy package to carry. I am proud to take care of my aunts, but it is overwhelming.

**I have three kids of my own, a wife who works, and it's happening to a lot of my friends. I have three times the responsibility of what most people have, but I see a lot of them struggling with it. We need a better system. It is a heavy package to carry.**

## Next Steps

Since its inception in the fall of 2007, the Family Caregiver Council has created a shared vision of how best to support caregivers. In considering how to address the needs of caregivers and help them sustain their valuable role in the community, the Council has identified the following important areas that should be focused upon: education so that individuals providing care recognize themselves as caregivers; information and outreach to identified caregivers; and the availability of and access to supports and services. NYSOFA, with the assistance of other state agencies, will continue to support the Council's efforts and the valuable contributions that they have made to date. The ongoing work will include:

- **Regularly Scheduled Meetings** – The Council will continue to meet periodically in person or by conference call.
- **Town Hall Meetings** – The Council will continue to sponsor NYSOFA's Town Hall Meetings to hear directly from informal and formal caregivers across the State.
- **Data Review** – The Council will continue to analyze data to identify effective ways to assist caregivers to continue to care for those they love. This will include reviewing the data from the caregiver questions contained in the 2008 Behavioral Risk Factor Surveillance System (BRFSS) Questionnaire administered by the New York State Department of Health, further analysis of data from the surveys conducted in 2008, and additional information gathering and data review on additional caregiver-related topics.
- **Support Coalition Building** – Caregiving is a multi-generational issue that affects people of all ages from all walks of life. Coalition building will enable information to be distributed to a wide and diverse group of individuals, agencies and organizations throughout the state about caregiving issues. This information can be used to promote innovative programs and approaches around better ways to support caregivers, promote public education and awareness, increase knowledge about availability and accessibility of community resources, track federal and state policy and legislation, and create communication strategies among providers.
- **Media Campaign** – The Council will promote completed products and discuss future efforts to bring awareness of caregiver issues.
- **Continue to Develop Recommendations and Plan Action Steps** – The Council will continue to develop recommendations and plan action steps to support and strengthen caregivers across the lifespan in New York State.

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## Appendix A: Family Caregiver Council Recommendations

The Family Caregiver Council developed recommendations that drew from the work accomplished in 2007 and 2008. These recommendations will continue to inform the work of the Council in 2009 and beyond. The recommendations are outlined below, and incorporate the following principles:

- Recommendations shall incorporate ethnic, racial, religious/spiritual, cultural, life-style diversity, sexual orientation, linguistic, age-related, and disability-related competencies.
- Recommendations should address caregivers caring for people across the lifespan and across all disability areas, and recognize their valuable role in supporting their loved ones.
- Recommendations should recognize that service needs must be considered for both the caregiver and the care recipient as a combined unit.

The recommendations are outlined within eight overarching topic areas in the table below:

1. Strengthen Services and Programs that Support Caregivers and Care Recipients
2. Increase Information and Outreach
3. Encourage Civic Engagement/Community Empowerment
4. Continue the Development of a State/Local Infrastructure
5. Increase Training/Education
6. Educate and Involve Business and Workforce
7. Improve the Rights of Caregivers
8. Enhance Housing Options and Supports

<b>TOPIC AREAS and RECOMMENDATIONS</b>
<p><b><i>1. Strengthen Services and Programs that Support Caregivers and Care Recipients</i></b></p> <p>In New York State, it is estimated that at least 80 percent of community-based long-term care for persons of all ages is provided by family or other informal caregivers. This voluntary assistance reduces public spending for long-term care supports and services and has an estimated annual economic value of \$25 billion in New York State. It is in the interest of the State to support family caregivers in their caregiving role. To continue to provide these services in difficult fiscal times, the current caregiver services/programs and housing options should be reviewed to determine how to best provide the most efficient and cost effective assistance to caregivers across the lifespan.</p> <ul style="list-style-type: none"> <li>• Identify and streamline funding for consumer-directed respite by addressing policy and/or regulatory barriers that inhibit providing respite services across systems and across the lifespan.</li> <li>• Support the development of a patient health care navigator program to pair trained volunteers with patients during discharge planning and post-discharge needs. The volunteers would provide assistance with escort, medication management, and compliance with the discharge plan.</li> <li>• Identify transportation and escorted transportation services provided to caregivers or care receivers by such agencies as aging, social services, health, veterans, and/or volunteer groups.</li> <li>• Support the development of a survey to better understand and address the needs of young</li> </ul>

caregivers in New York.

- Strengthen services to caregivers across the lifespan.
- Develop a statewide network of Regional Caregiver Resource Centers (RCCEs) that provide and coordinate a range of services including respite care, counseling and support groups; training; transportation; care coordination and advocacy; and training for caregivers. These centers should build on existing local grassroots efforts and coordinate with county government.
- Continue to fund Office of Children and Family Services regional Kinship Caregiver Programs and coordinate research data.

## ***2. Increase Information and Outreach to Informal Caregivers Across the Lifespan***

Many caregivers are unaware of available services until they are faced with a crisis. The New York State *Caregiver Services Survey* (2008) results indicate that even key informants (case managers, information and referral specialists, etc.) lack knowledge of some available services in their communities. Efforts must be made to increase information about caregivers programs and improve outreach efforts to reach caregivers across the state.

- Increase access to streamlined information and assistance about community supports and services by supporting **NY Connects: Choices for Long Term Care** as the principle vehicle for objective information about the array of options available in communities to support consumers, caregivers and professionals. Information should be available through telephone calls, website, in person at home or an office. **NY Connects** staff should help consumers and caregivers navigate the long-term care system and better understand the resources available to caregivers of all populations.
- Work closely with hospitals, clinics, and doctor's offices to promote awareness of **NY Connects** as a vehicle to provide information about caregiver services.
- Continue to hold community meetings, e.g., Town Hall Meetings, around the state to provide a forum for caregivers to share their stories, discuss their needs, and what services must be provided to allow them to continue in their valuable caregiving role.
- Promote the theme, *You Care for Them, We Care For You*, that was developed in 2008. This message can be used on printed materials, web sites, etc. The video message should be developed to use as a Public Service Announcement and distributed widely to reach caregivers who have entered or are just about to enter that moment when they realize their lives revolve around caring for a loved one.
- Educate elected officials in the cost benefit that caregivers provide to New York State and encourage them to strongly support family caregiver programs and services across the lifespan.
- Produce and widely disseminate Caregiver Toolkits that provide information to assist caregivers to plan for their caregiving role and responsibilities.

## ***3. Encourage Civic Engagement/Community Empowerment to Support Informal Caregivers***

The federal, state, and local governments alone will not be able to meet all of the needs of caregivers, particularly in the current fiscal environment. All stakeholders must be identified and engaged in finding ways to support caregivers across the lifespan.

- Promote volunteerism by engaging community groups, Naturally Occurring Retirement Communities (NORCs), Neighborhood Naturally Occurring Retirement Communities (NNORCs), and high school organizations (for example, the Gate Keeper Program may be used as a model of non-traditional referral sources who come into contact with older adults and people with disabilities through their everyday activities and are trained to look for signs and symptoms that may indicate the person is in need of assistance).
- Identify and study outcomes of existing grass roots efforts such as volunteers providing transportation, food banks and other services in their communities.

#### ***4. Continue the Development of a State and Local Infrastructure for Caregiver Services and Supports.***

To best support caregivers across the lifespan it is necessary to strengthen and develop the state and local infrastructure. The Council continues to assist in this development by identifying barriers to caregiving, gaps in services, innovative services and best practices, and strategies to link and coordinate caregiver support programs and services.

- Develop a statewide, cross-disability, intergenerational caregiver coalition. This coalition will include but not be limited to caregiving and respite programs of the Area Agencies on Aging, programs for caregivers of all ages administered by publicly and privately-funded community and faith-based agencies, local caregiver coalitions both new and emerging, intergenerational caregiving and respite programs, cross-disability caregiving and respite programs, kinship care and grandparent caregiver stakeholders, the Coalition of Alzheimer’s Association Chapters, and any Regional Caregiver Centers for Excellence (RCCE) in New York State. This new coalition will act as a united voice on behalf of caregivers to advocate for public policy, legislation, and needed programmatic changes that support caregivers (e.g., Lifespan Respite Act, etc.). The coalition should work in concert with the Family Caregiver Council to:
  - Develop a common goal and mission supporting caregivers across the lifespan.
  - Provide a process for decision-making and staff support.
  - Identify potential partners.
  - Be sensitive to and inclusive of ethnic and culturally diverse groups and assure that cultural, linguistic, age-related, sexual orientation and disability competencies are addressed.
  - Build an advocacy agenda for caregivers across the lifespan.
  - Develop a cohesive and comprehensive communication strategy regarding caregiver-related issues in New York State.
  - Inform and educate the public about caregiver issues.
  - Assure education and training about caregiving is available and accessible to all caregivers.
  - Build on public/private partnerships.
  - Involve employers/business community.
  - Coordinate annual statewide and/or regional caregiver conference(s).
- Continue to work closely with state agencies acting as ex officio members of the Council. This work should include modifying assessment processes/tools across state agencies to identify the skills, needs and environment(s) of the caregiver and the care-receiver, recognizing them as a combined unit.

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### ***5. Expand Training and Education for Informal and Professional Caregiving***

Family/unpaid caregivers and paid caregivers would benefit from more training and education. The RCCEs, although not yet developed, would help address this need.

- Develop flexible person- and caregiver-centered training/education (on-line, in-person and group settings) should be developed. Specific topics include addressing functional and emotional areas, and training and education should be culturally relevant to the caregiver(s). Suggested training/education topics include:
  - Medication management (for unpaid caregivers).
  - Falls prevention (for both paid and unpaid caregivers).
  - End-of-life issues (for both paid and unpaid caregivers).
  - Family support training/working together (for both paid and unpaid caregivers).
  - Where to find assistance (for unpaid caregivers).
  - Training in caring for a person with dementia (for both paid and unpaid caregivers).
  - More training for in-home and nursing home staff (for paid caregivers).
  - Legal and medical issues for caregivers (for unpaid caregivers).
  - Support groups (for unpaid caregivers).
  - Stress reduction (for unpaid caregivers).
  - Financial planning (for unpaid caregivers).
  - Shared best practices (for both paid and unpaid caregivers).

### ***6. Educate and Involve Business and Workforce in Caregiving Issues***

The impact of caregivers on the workplace is substantial. Employers should be educated and involved in finding creative solutions to allow caregivers to remain a productive part of the work force. This will help caregivers who fear losing income and benefits should they no longer be able to work due to their caregiving responsibilities

- Provide additional support to caregivers by educating and involving employers and the workforce in creative solutions to allow caregivers to remain a productive part of the workforce.

### ***7. Improve the Rights of Caregivers***

- Support financial security for caregivers by:
  - Exploring options for improving financial security of grandparents and other kinship care provider and assessing costs/benefits.
  - Explore the possibility of including caregivers and care recipients in the STAR tax relief program to provide credits for households that include caregivers and care recipients.
  - Addressing issues related to inadequate or loss of health insurance due to caregiving responsibilities.
- Assist caregivers dealing with barriers in the health care system by:

- Encouraging caregivers and care recipients to use electronic storage of executed Health Care Proxy and Living Will documents to ensure health care providers can access these directives.
- Expanding regulations that require communication to patients be provided in the language and method of communication (e.g. sign language) for designated caregivers.
- Creating a caregiver's rights palm card that lists numbers to call for assistance with caregiver's rights and identifies the caregiver as an informed advocate.
- Promoting the use of training material for health and social services personnel to raise their awareness and acceptance of the role of caregivers.
- Providing health and social services staff and caregivers with the skills needed to recognize the signs of cognitive deficits and dementia in care recipients.

#### **8. *Enhance Housing Options and Supports***

- Collaborate with the New York State Division of Housing and Community Renewal (DHCR) to establish a program to develop and evaluate affordable innovative housing alternatives that would enable family and other caregivers to provide assistance to individuals so that they can remain in their community and homes of choice
- Continue and expand the Access to Home Program to increase assistance with obtaining environmental/adaptive use modifications in homes that enable caregivers to provide care and supportive assistance to individuals that would otherwise be placed in a higher level of care.
- Support the ongoing efforts conducted under the Housing, Planning, and Zoning Initiative, which is being implemented jointly by NYSOFA and the New York State Department of State.
- Strengthen and promote New York State housing-related programs designed to assist older adults to remain in their own home and community, such as NYSOFA funded Naturally Occurring Retirement Communities (NORCs) and the DHCR Access to Home Program.

## **Appendix B**

### **Town Hall Meetings: Overview and Summary**

Planned by NYSOFA and sponsored by the Family Caregiver Council, eight Town Hall Meetings were held in 2008 and 2009. The purpose of the Town Hall Meetings is to hear directly from caregivers across the lifespan.

A panel consisting of Family Caregiver Council members, NYSOFA executive staff, and local Area Agencies on Aging Directors received comments and heard stories from caregivers about their experiences and ways in which they could be supported. The meetings were held at the following locations:

- Rensselaer County - February 8, 2008
- Washington County - April 23, 2008
- Dutchess County - April 24, 2008
- Somos El Futuro Conference – Albany - April 25, 2008
- Statewide LGBT Health and Human Services Network – Albany - April 28, 2008
- Suffolk County - May 23, 2008
- St. Lawrence County – June 13, 2008
- Orange County – November 9, 2009

The meetings were structured to encourage people to participate and testify about:

- What are the most critical needs you face as someone who provides care to a family member or other individual in the community?
- What assistance and supports are most critical to you, your family, and other informal caregivers who are assisting loved ones with everyday tasks in their homes and communities?
- What barriers do you face as a family caregiver? What makes it hard for you to provide care?
- What innovations are needed to support caregivers?
- Are there “best practices” that can be shared with others?

The testimony from speakers at each meeting was compelling and a valuable resource to the Family Caregiver Council as they began to draft recommendations for 2008-09. Input from caregivers at the Town Hall Meetings framed the many challenges and rewards of providing care to a loved one and also included information to help develop future policies about services that help and support caregivers, systemic long-term care issues, and suggestions to strengthen and support caregivers in New York State. Samples of stories shared by caregivers at Town Hall Meetings were included earlier in this Report.

#### **Themes and Issues Raised by Speakers**

##### **Why Caregivers Need Help**

Caregivers identified the many rewards of providing care to loved ones or family members, and also identified some of the challenges they face, including a sense of isolation, stress, and frustration related to competing demands; not knowing where to turn for help, guilt about not being able to do enough to support the care recipient, and the emotional toll of dealing with end-of-life issues. Specific challenges raised by caregivers included:

- The stress of caregiving presents itself physically, emotionally, and financially. Caregivers expressed concerns about their own physical and mental health.
- Concerns were expressed about the loss of income or diminishing resources related to the high cost of care.

- Older caregivers of mentally ill or developmentally disabled older children expressed concerns about limited options for ongoing and future care for their children.
- Gay, lesbian, bisexual, and transgender populations reported the same experiences and challenges of other caregivers, but also indicated their caregiving was complicated and compounded by the complexities of discrimination, injustice, legal issues, and lack of knowledge and understanding.
- Grandparents and kinship caregivers reported dealing with many legal issues surrounding the care of a child.
- Hispanic caregivers reported the need to address cultural issues surrounding caregiving.

## **Services That Help and Support Caregivers**

During the Town Hall Meetings, caregivers clearly articulated those supports and services that help them to continue in their caregiving role. When available, these services help caregivers to reduce stress and isolation, to understand that they are not alone in their experiences, to realize that they are assuming a valuable role, and that they, too, deserve support. These services should be tailored for particular populations including but not limited to grandparents caring for grandchildren, caregivers of Alzheimer's patients, and caregivers of individuals with early stages to more severe stages of dementia. The services that were mentioned numerous times by caregivers include the following:

### *Direct Caregiver Support*

- Caregiver support groups to reduce stress and isolation of caregiving.
- Caregiver support groups for caregivers with similar circumstances.
- Training for caregivers to improve skills and increase capacity to care for others.
- Caregiver counseling and family mediation to bring the family together to discuss issues and roles of decision making.

### *Respite*

- Respite services that provide a break to caregivers and emergency respite services.
- Respite services that include meaningful activities for the care receiver.
- Consumer directed respite care programs.

### *Facility-Based Respite*

- Social adult day care and adult day health care that provide respite for caregivers and also provide valuable support to the care recipient.

### *Home and Community Based Services*

- Information and assistance for all caregivers, including long distance caregivers.

### *Legal Services*

- Mediation services for families who must come to an agreement on caring for a loved one.
- Legal assistance to complete documents, e.g. Advance Medical Directives, Adult Guardianship.

### *Transportation*

- Transportation - especially in rural areas.

### *Financial Support*

- Financial planning for caregivers.
- Financial support to working caregivers who reduce their work schedule to care for their loved ones.

## **Systemic Long Term Care Issues**

Caregivers also identified systemic long-term care issues that need to be resolved in order to make their caregiver role easier. These issues, not necessarily related to direct support to caregivers, include availability of a professional workforce, transitions among programs and services, and availability of housing options. Additional issues that were raised include:

- Workforce issues and the need for more qualified workers, including aides.
- Low pay of home and facility-based workers.
- Aging out of programs and impact on the family.
- Lack of availability of services for middle income families in need of assistance.
- More research dollars needed for medication trials.
- Educate the medical community about geriatric medicine.
- Availability of affordable housing.
- Lack or denial of Long Term Care Insurance for individuals with post-traumatic stress.

## **Suggestions to Strengthen and Support Caregivers in New York State**

Based on many collective years of caregiving, Town Hall presenters (both providers and caregivers) were able to articulate a variety of suggestions to strengthen and support caregivers. The suggestions focused on increasing caregivers' knowledge of services and their own role as a caregiver, ways to better support caregivers financially, strategies to increase the workforce to better support caregivers, the connection between caregiver issues and other major initiatives, and program enhancements to existing services.

### *Public Education*

- Create more public awareness of caregiver services.
- Increase recognition and self identification of oneself as a caregiver.
- Develop a consumer education campaign on Alzheimer's disease and other dementias to educate consumers that these dementias are not part of the normal aging process.
- Education for family and friends to better understand Alzheimer's Disease and other dementias so that they will better support the caregiver.
- Promote awareness of laws that ensure residence and family councils in institutions.

### *Financial Support*

- Develop a funding mechanism for long term care similar to unemployment insurance where funds are set aside over one's lifetime. This would be helpful for individuals who cannot afford long term care insurance.

### *Civic Engagement*

- Tap into the pool of retired professionals, either paid or volunteer, to share their expertise to provide respite, training, financial counseling, and other support services.
- Use non-traditional approaches to reaching out to volunteers and caregivers in places such as Starbucks, WalMart cafeterias, bowling alleys, Off-Track Betting locations, bookstores, and gun clubs – many of which can help programs to reach male caregivers.

### *Collaboration*

- Ensure coordination between various local community initiatives and caregiver support services.

- Create collaborations between the aging network and the health care system.

*Program Enhancements*

- Ensure programs assess the needs of the caregiver, family and the care-receiver and are responsiveness to changing population dynamics, including ethnic, language and cultural differences. One suggested approach was adoption of the hospice model, which assesses the entire family's needs and provides supports to the family as a whole.
- Enhance central repositories of services or somewhere to find services (e.g., Caregiver Centers for Excellence, and **NY Connects**, etc.).
- Provide greater assistance for grandparent/relatives caring for children, who struggle with finances.
- Increase (double) the child only grants for grandparents caring for grandchildren.
- Provide tuition assistance to young adults going to college while acting as a caregiver and to grandchildren being raised by grandparents.
- Address and recognize mental health needs in caregiver programs.
- Change Mental Hygiene Law Article 81 regarding guardianship.
- Expand grief counseling and support.
- Provide insurance for volunteers who transport clients.
- Expand housing options such as home sharing.
- Recognize the unique needs of caregivers caring for grandchildren and a spouse or parent simultaneously and link them to existing services and programs that can support their needs.

