Older New Yorkers and the NYS Olmstead Plan

The New York State Association of Area Agencies on Aging* provides this report, along with documents obtained through AARP, as a follow-up to the roundtable on March 15, 2013 convened by Roger Bearden, Special Counsel to Governor Andrew Cuomo for Olmstead. The Council of Senior Centers and Services of New York City (CSCS) recently sent a document to Roger Bearden regarding Olmstead and older adults in New York City. The introductory remarks below mirror the CSCS document, as we share the same perspective. The CSCS document provided population data specifically for New York City; our document includes statewide information to provide a comprehensive picture of New York State. AARP contributed the section on caregivers. (*Name changed to Association on Aging in New York in July 2013)

Following the 1999 United States Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), the Americans with Disabilities Act (ADA) required public disabled service providers to administer their services in the most appropriate integrated setting. In order to comply with the regulation in the face of an aging population, it is incumbent that New York State provides the necessary resources to maintain at-risk seniors in the community.

Much of the discussion around the implications of the Olmstead decision focuses on treatment and service options for nonelderly persons with disabilities. However, this case also applies to older adults who have long-standing disabilities, or who have experienced disabling conditions during the elder years, or who can be characterized as disabled because of normal aging-related physical and mental declines that have an impact on their ability to live independently.

Several factors place the New York State population aged 60 and over at risk for institutionalization in the absence of adequate supports to maintain them in the community. The rapid growth of the senior population means that the challenges associated with helping older people remain in the community will grow.

As the data below suggest, this population is vulnerable to institutionalization in the absence of adequate social program supports and should therefore be included in the New York State Olmstead Plan submission to the Department of Justice.

Profile of New York State’s Older Population

- **Rapid Population Growth.** New York State is fourth in the nation in the number of adults age 60 and over, with a population of about 3.7 million (1.3 million in New York City). The 60-plus cohort increased 15% statewide between 2000 and 2010, and this figure will only increase as the post-war boomer generation continues to age. Across the state, the 60-plus age group is increasing rapidly, while the under-60 population is shrinking in many counties. (See attached demographic charts prepared for the 27 Congressional Districts in New York State.)

- **Living Alone, Often Without Supports.** In New York State, 28.9% of the senior population live alone according to US Census/American Community Survey (ACS) sample results covering 2009-2011 (31.2% in New York City and 27.5% in the rest of the state). Without aging services, seniors
living in isolation who lack the informal support of family members are further put at risk for Medicaid spend-down and higher levels of care such as nursing homes.

- **Frailty.** An estimated 866,547 persons aged 65 and over are considered to have a disability as defined by the Census Bureau (ACS, 2009-2011). Disability due to dementia affects over half the population aged 85 and over. These seniors have difficulty or are unable to perform many of the in-home services that the Expanded In-home Services for the Elderly Program provides, such as meal preparation and bathing assistance.

- **Poverty.** While a frail and isolated population is already at risk for nursing home care, vulnerability also extends to those living in poverty. New York State’s poorest seniors, i.e., those living below 100% of the Federal Poverty Level (FPL), account for 11% of the senior population in the state, or 286,268 individuals in New York state. In New York City, 15.5% of the senior population is below 100% FPL, or 210,000 older adults.

Further, people in the range of roughly 125% to 200% of FPL are by-and-large ineligible for certain public programs such as Medicaid. This group comprises 405,493 seniors statewide (209,000 in New York City), and while they face economic stresses similar to those living below 100% of FPL, they must make do with even fewer social supports. Cutbacks in the federal, state and local budgets have curtailed AAA services.

**Profile of Older New Yorkers Receiving AAA Services**

Programs and services provided though the 59 Area Agencies on Aging (AAAs) and their subcontractors keep frail, low income older persons living independently in their homes and communities for as long as possible. Many of these individuals are at risk of nursing home care and/or becoming eligible for Medicaid. Predictors of nursing home entry include demographic characteristics, socioeconomic status, health status and physical functioning, living arrangements and family structure and availability of support (Miller and Weissert 2000; Gaugler et al. 2007). A key to nursing home avoidance and Medicaid cost containment is a package of low-cost community based services for older adults that are at imminent risk.

**NY Connects: Choices for Long Term Care**

NY Connects is a statewide, locally based point of entry system that provides one stop access to free, objective and comprehensive information and assistance on long term services and supports (LTSS). NY Connects links individuals of all ages needing long term services and supports, as well as their caregivers, to the services and supports they need to maintain independence to the extent possible, regardless of payment source. NY Connects is operated at the local level in most counties by AAAs, in conjunction with partner agencies, throughout the state, except New York City.

**COMPASS and Case Management**

The AAAs utilize a COMPASS (Comprehensive Assessment for Aging Network Community-Based Long Term Care Services) assessment tool to determine the individual’s current status with respect to housing, health, nutrition, psycho-social status, IADLs and ADLs, and other information. A critical component is the “informal support status” section which acknowledges the importance of the care provided by caregivers (see page five for more details on caregiver contributions). The COMPASS elements are used to develop the care plan. The assessment process and case management services assist older adults and their caregivers to use their own resources appropriately and supplement these existing resources with non-medical long term care services and supports as necessary. The following AAA programs provide services for older adults with risk factors such as frailty, poverty and living alone without supports.
Expanded In-home Services for the Elderly Program (EISEP)

The Expanded In-home Services for the Elderly Program (EISEP) provides non-medical in-home services, case management, non-institutional respite and ancillary services to older New Yorkers that are not yet eligible for Medicaid or other public programs. Just under half (44%) of the EISEP clients have incomes at or below the poverty level, putting them at risk of spend down to Medicaid.

Virtually all EISEP customers meet the programmatic eligibility requirements for Medicaid personal care services and many are very close to being financially eligible, according to the New York State Office for the Aging’s 2008 study *Sustaining Senior Independence*.

**EISEP Characteristics (State Fiscal Year 2011-12)**

- **Frailty.** Using the New York State Office for the Aging (NYSOFA) definition, 89% of those receiving EISEP are considered frail.
- **Age.** There’s a correlation between age and frailty: three-quarters of the EISEP consumers are over age 75.
- **Poverty.** 43% live at or below 150% of the FPL.
- **Access to Services.** The availability of community-based services like EISEP is critical in keeping eligible seniors out of higher levels of care such as nursing homes. Despite their effectiveness, these services are underfunded and overloaded.

- **Multiple Needs.** Often, the assessment process reveals that a package of services is needed to address the unique circumstances of an individual. Seniors receiving personal care services through EISEP have multiple needs: more than 55% receive three to five services and an additional 15.4% receive six or more services.
Community Services for the Elderly (CSE)

The Community Services for the Elderly (CSE) program was designed to improve cooperation and coordination among providers of community services to assist frail people who need help in order to remain in their homes and participate in family and community life. The program offers flexible service options to meet the unique needs of senior citizens in communities throughout the state. Just over 60,000 older adults received services through CSE in State Fiscal Year 2011-12.

CSE Population Characteristics
(State Fiscal Year 2011-12)

- 48% are frail and disabled
- 51% live alone
- 62% are over the age of 75
- 30% live below 150% FPL

Home Delivered Meals Program (HDM)

The nutrition program overseen by the NYS Office for the Aging and operated locally by the Area Agencies on Aging includes home delivered meals (HDM), congregate meals, and nutrition education and nutrition counseling. The home delivered meals component serves a frail, low-income segment of the older population. The nutrition program is funded through several sources, including the federal Older Americans Act, state-funded Wellness in Nutrition program, local match and participant contributions.

HDM Population Characteristics
(State Fiscal Year 2011-12)

- 42% percent are 85+
- 59% percent live alone
- 80% have two or more chronic health conditions
- 40% live below 150% FPL
The Growing Contributions and Costs of Family Caregiving

Over 2.2 million informal caregivers – friends, family and neighbors – provide direct care to people of all ages with disabilities. An AARP review of the NYSOFA budget revealed that less than $3 million in state funds are specifically appropriated for direct assistance to informal family caregivers.

If the work of these caregivers had to be replaced by paid home care workers, the cost would be $32 billion annually in New York State (Valuing the Invaluable: 2011 Update - The Growing Contributions and Costs of Family Caregiving, AARP, page 27, Table B1).

A measurement of state-level performance of long term services and supports (LTSS) that provide assistance to older people and adults with disabilities examined four key dimensions of LTSS systems, one of which was support for family caregivers. New York State ranked 48 out of 50 with respect to support for its family caregivers. (A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. Produced cooperatively by AARP, the Commonwealth Fund and the SCAN Foundation. September 2011.)

The New York State Office for the Aging’s 2009 report, Sustaining Informal Caregivers: Caregiver Support Programs Participants Survey concluded that caregiver support services and community resources help caregivers to provide care longer and may also help delay or prevent nursing home placement. This report also showed:

- Caregivers spend 62.6 hours a week providing care.
- 36% reported their receivers of care cannot be left alone at home.
- 42% reported that their receivers of care can only be left alone for short periods of time or need to be checked on in person several times a day.

The convergence of several trends raised concerns about greater strain placed on already overburdened families in the future, according to AARP’s Valuing the Invaluable: 2011 Update – The Growing Contributions and Costs of Family Caregiving. Changes in family structure, such as delayed marriage and childbirth, high rates of divorce and smaller family size, mean that there will be fewer people in a family to act as caregivers.

A recent analysis of 20-year trends in family caregiving and LTSS found that until the mid-1990s, family care was being augmented by some paid help, but the trend has reversed and more family caregivers today are left to carry the load alone. (Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community: Data from the National Long-Term Care Survey, AARP Public Policy Institute Research Report AARP, 2010)
Evaluation Reports on Nursing Home Diversion

During the Olmstead roundtable discussion on March 15, 2013, evaluation reports were referenced as substantiating the effectiveness of providing community-based services for low-income individuals that were nursing home eligible, enabling them to live in the community. An electronic copy of these reports was provided after the roundtable, and another copy is provided with this document. The following is a summary of the findings.

The New York State Office for the Aging received two grants, a Nursing Home Diversion Modernization (NHDM) grant in 2008 and a Community Living Program (CLP) grant in 2009, from the U.S. Administration on Aging targeted at individuals not yet eligible for Medicaid, but who were at high risk of nursing home placement and of spending down their income and assets to the Medicaid level. Both grants allowed for an optional consumer-directed model of care to help individuals maintain their independence and remain in their communities.

Report Citations


Outcomes Data

- All 93 of the program participants were at high risk for nursing home placement and of spending down their income and assets to the Medicaid level. (NHDM, 2011)

- All 114 of the program participants were at high risk for nursing home placement and of spending down their incomes and assets to the Medicaid level. (CLP, 2012)

Nursing Home Placement

- 81% of the 93 participants in the program did NOT enter a nursing home during the program period. (NHDM, 2011)

- 89% of 114 participants did NOT enter a nursing home during the program period. (CLP, 2012)
Medicaid Spend-Down

- 83% of 93 participants did NOT spend down to Medicaid. (NHDM, 2011)
- Only 1 of 114 participants entered Medicaid supported home care. Note, however, that 9 participants died and 3 moved out-of-state during the course of the project. (CLP, 2012)

Cost analysis

- The actual monthly cost for all 93 NHDM participants was $232,469. The costs would be much higher if these 93 were to spend-down to Medicaid and either enter a nursing home or receive Medicaid home care. (NHDM, 2011, see Figure 1)

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- The actual monthly cost for all 114 CLP participants was $253,764. The costs would be much higher if these 114 individuals were to spend-down to Medicaid and either enter a nursing home or receive Medicaid home care. (CLP, 2012, see Figure 1)

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The Older Americans Act and Low-Care Nursing Home Residents

A 2012 report, *The Relationship between Older Americans Act Title III State Expenditures and Prevalence of Low-Care Nursing Home Residents*¹ examined national Older Americans Act (OAA) data to determine whether these non-Medicaid services had an impact on keeping seniors in the community rather than being admitted to nursing homes. Excerpts from the report highlight the principal findings and conclusions:

**Objective.** To test the relationship between older Americans Act (OAA) program expenditures and the prevalence of low-care residents in nursing homes (NHs).

**Data Sources and Collection.** Two secondary data sources: State Program Reports (state expenditure data) and NH facility-level data downloaded from LTCfocUS.org for 16,030 US NHs (2000-2009).

**Principal Findings.** Results indicate that increased spending on home-delivered meals was associated with fewer residents in NHs with low-care needs.

**Conclusions.** States that have invested in their community-based service networks, particularly home-delivered meal programs, have proportionally fewer low-care NH residents.

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The closing paragraph of the article supports the philosophy embraced by the AAAs and Aging Services Network in New York:

“This article reveals that despite efforts to rebalance LTC, there are still many NH residents who have the functional capacity to live in a less restrictive environment. States that have invested in their community-based service networks, particularly home-delivered meals, have proportionally fewer of these people than do those states that have not. The challenge for states and CMS will be to build and invest in systems and programs that divert unnecessary NH placement for individuals who can be sustained in the community.”

Conclusion

The population of New York is aging rapidly. Risk factors such as frailty, poverty and living alone without supports are also on the rise. Predictors of nursing home entry include demographic characteristics, socioeconomic status, health status and physical functioning, living arrangements and family structure and availability of support (Miller and Weissert 2000; Gaugler et al. 2007).

The state’s Area Agencies on Aging are positioned to assist older New Yorkers and their caregivers to remain in their homes and communities as long as possible, thus avoiding nursing home placement where appropriate. However, due to limited resources, there is a considerable gap between the number of older adults currently served and the number that are eligible for these supportive services.

Three reports discussed earlier provide evidence to support the argument that expanding the capacity of the AAAs to provide home and community based services would enable older New Yorkers to live in the least restrictive setting. In the absence of adequate social program supports, older adults with the aforementioned risk factors are vulnerable to institutionalization and should therefore be included in the New York State Olmstead Plan submission to the Department of Justice.

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