

**A Preliminary Report on the Long Term Care Councils  
Established through the NY Connects Program and  
Their Impact on the Long Term Care System in New York State**



**Produced by the New York State Office for the Aging**

**IN DEVELOPMENT**

## INTRODUCTION

In early 2006 the New York State Office for the Aging (NYSOFA) and the New York State Department of Health (NYSDOH) issued a Request for Application (RFA) to all counties to establish entry points for long term care Information and Assistance throughout the State. This coordinated system for accessing long term care information and services in New York State has become known as **NY Connects: Choices for Long Term Care**. NYSOFA and NYSDOH received an overwhelming response from counties eager to participate in the **NY Connects** program. Nearly every county decided to participate in **NY Connects**, which started on October 1, 2006<sup>1</sup>. Counties are now in the second year of operation.

In the first year of **NY Connects**, counties were required to establish a Long Term Care Council (LTCC), along with the provision of accurate and unbiased Information and Assistance on long term care services. These Councils are comprised of consumers, caregivers, health care professionals, and aging and health providers in the community, who have an understanding of the county's long term care system and an interest in improving the system. The purpose of the Long Term Care Council in each county is to examine and analyze the local long term care system, identify gaps and duplication in the system, and come up with solutions and strategies to address the identified gaps. The Long Term Care Council is thus integral to making improvements to the long term care system in each county, as well as in New York State. To date, 52 programs in total, which includes 51 counties and St. Regis Mohawk, have identified the members of their local Long Term Care Councils.

This paper will:

- Present information on the composition of these local Long Term Care Councils, describing the different groups of individuals who are serving on these Councils and the various ways in which these Councils were formed
- Discuss what some of the local Long Term Care Councils have accomplished to date
- Provide a glimpse of what the counties plan to do with their Long Term Care Councils in this next year

The quarterly reports submitted by the local **NY Connects** programs and the minutes from Long Term Care Council meetings were used to develop this paper.

## COMPOSITION AND OPERATION OF LONG TERM CARE COUNCILS

To date there are approximately 1,456 individuals identified or participating on local Long Term Care Councils throughout the State.

The Long Term Care Council for each county/program must be representative of the community it serves and reflect the ethnic and economic diversity of the service area

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<sup>1</sup> 59 counties, St. Regis Mohawk, and Seneca Nation were eligible to apply for the RFA. Seneca Nation and Oswego decided not to participate in **NY Connects** at the time of the RFA.

population. The Council must include consumers representing the populations served (i.e. older adults and individuals of all ages with disabilities), community-based and residential long term care providers, and advocacy groups.

In an effort to provide county flexibility in recruitment procedures, the State did not mandate any specific recruitment methods. The following techniques have emerged as the most popular methods used to identify and recruit new LTCC members:

1. Providers across the county are invited to attend a kick-off meeting and are given the option to serve on the Council
2. Elected officials are appointing and approving members
3. Lead agencies, such as the Department of Social Services and Area Agencies on Aging, are identifying and recruiting members

The State has, however, provided guidance to the counties with regard to the formation of their Long Term Care Councils through the distribution of a Technical Assistance Resource Document on Long Term Care Councils; the Resource Document gives suggestions on how to establish a successful Long Term Care Council, such as finding a strong facilitator for the meetings. Additionally, the State is planning to hold regional trainings that will focus on how counties can further develop and strengthen the membership of their Councils.

### **Examples of County Membership**

- The Albany County **NY Connects** has standing members from all relevant local government agencies, adult day care and home care programs, nursing facilities, Caregiver Association, Alzheimer's Association, Paraprofessional Health Care Institute, Catholic Charities, the Medical Society of Albany County, Albany County Executive's Office, Consumer Directed Choices, the Independent Living Center that serves the region, the Department of Children, Youth and Families/Division for Children with Special Needs, and most importantly, people in Albany County who use long term care services.
- Nassau County has a broad spectrum of Long Term Care Council members represented. Their Council is comprised of the following agencies: Department of Social Services, Department of Health, Senior Citizen Affairs, St. Mary's Hospital for Children, Long Island Center for Independent Living (their Independent Living Center), Parker Jewish Institute for Health Care and Rehab, North Shore/Long Island Jewish Health Systems, Alzheimer's Association of Long Island, NYS Association of Long Island, Cancer Care of Long Island, AARP, the Variety Child Learning Center, a consumer, and a caregiver.
- Rockland County has a large representation of consumers and caregivers on their Council: 14 out of their 35 members are consumers or caregivers. In addition to representatives from the Department of Social Services, Office for People with Disabilities, and Health and Human Services, the Rockland County Long Term Care Council also has hospital providers, adult homes, home aides, and the Alzheimer's Association serving on the Council.

- Yates County boasts a large Long Term Care Council with 71 members, including some consumers and caregivers. They have representatives from the Yates ARC (a non-profit for people with developmental disabilities), Alzheimer's Association, the Council of Churches, the Finger Lakes Health Systems Agency, Lifespan, a Traumatic Brain Injury support group, AIDS Rochester, the Veterans Agency, the Child & Family Resource Center, the Advocacy Center, the Department of Social Services, and the Office for the Aging. The County Administrator also sits on the Council.
- Oneida County has much smaller Council with 17 members, but they have been able to bring multiple stakeholders to the table. Council members include the following: a gerontologist, an academic from Mohawk Valley Community College, the United Way, the Independent Living Center, faith-based organizations, Visiting Nurses, Housing, and Board of Cooperative Educational Services (BOCES).

The Long Term Care Councils must all have governing policies in place, which address recruitment, selection, membership criteria, attendance, meeting frequency, and the process for documentation and follow up of meeting outcomes. Several counties have already met this requirement and have formal bylaws and policies to determine how their Long Term Care Councils should run and operate.

## **METHODS FOR GAP ANALYSIS**

The Long Term Care Council has played a vital role in conducting a gap analysis of the local long term care system. Counties reported conducting interviews and focus groups, along with distributing surveys and questionnaires to their Long Term Care Council members, who identified specific gaps and service needs in their community. The feedback and input provided by the LTCC members have helped counties identify key issues and issues around long term care. Members of LTCC in one county reported that they were gathering statistical information on the county's community resources and the demographics of the population to learn who the users of the long term care services are in that county.

Some counties reported using an independent subcontractor to conduct a long term care analysis in their county. The subcontractors were used to examine existing entry and transition points to long term care services, as well as identify gaps in the county system and offer recommendations on how to improve the system.

## **IDENTIFICATION OF GAPS AND BARRIERS**

Counties have made significant progress in identifying the gaps in services and the many barriers that individuals face in accessing long term care services. Based on a review of counties' narrative reports and Long Term Care Council minutes, several themes have emerged. Counties have identified the following as areas to address:

- Caregiver support
- Transportation
- Housing options
- Lack of community-based services
- Coordination of services

### **Caregiver Support**

- Onondaga County's Long Term Care Council recognized the lack of adequate support available for caregivers, and created a sub-group dedicated to the analysis of caregiver supports. Onondaga County plans to reach out to Syracuse University to discuss the possibility of creating an online video clip in an effort to lead caregivers to the resources and supports they need. A host of caregiver resources are currently provided on the Onondaga County Office of Aging & Youth's county website. **NY Connects** of Onondaga County hopes to expand upon those resources by giving individuals access to caregiver blogs and online forums. Onondaga County also hopes to host a public forum to allow community members an open space to talk about caregiver issues and create community solutions.
- Delaware County also acknowledged the financial and emotional burden that caregivers may face in caring for a family member or a loved one. Their recommendation is to give caregivers income supports through tax deductions, tax credits or other stipends. The County also calls for more training, support groups, volunteer programs and crisis intervention services through the Office of Aging, Alzheimer's Association and County Public Health Department.

### **Transportation**

- Orleans County noticed a lack of transportation services for individuals after three o'clock on weekdays and on the weekends. The Long Term Care Council plans to invite a speaker from the Orleans Transit Service to their next Council meeting.
- Dutchess County's Long Term Care Council also identified transportation as a gap/barrier, in addition to home health care aides and how to reach the non-English speaking population. Their Long Term Care Council plans to distribute a summary of these issues to the Council members to help them prioritize what issues to work on first.
- Ontario County reported that there is a lack of transportation services available for individuals who are having outpatient surgical procedures. The County sent a letter to the Red Cross to see if they could get volunteers who could transport individuals to a hospital or a doctor's office for a medical procedure and safely back home again.
- Niagara County recognizes the need to develop a comprehensive plan to address the transportation needs of older adults and individuals with disabilities.
- Because of the rural nature of the County, the availability of transportation continues to be a problem in Otsego County, particularly for individuals with accessibility issues. The County also reported problems with crossing county lines.

### **Lack of Community-Based Services**

- Delaware County's Long Term Care Council found that there is a lack of community-based services to help individuals live independently and remain in their homes. They noted that they do not have any adult day services.
- Lack of adult day services has been identified by other counties as a gap as well. The Long Term Care Council in Orleans County stated that there is a need for social adult day services in their county, and they intend to find out how other counties are funding such programs.
- According to Franklin County, the recent changes to the Weatherization Assistance Program (WAP), a program that has traditionally helped individuals with their energy-related costs and improved the safety of their homes through energy-efficient measures, has created problems in their county. The County reported that because the WAP can now only be used to pay for modifications when it relates to weatherization issues, not health and safety issues, individuals who need specialized ramps or other home accommodations, have been struggling to find other programs that will pay for these home modifications. LTCC members discussed the need to compile a list of resources to remedy this issue.
- Several members of Onondaga County's LTCC identified the lack of funding for a spectrum of community long term care programs.

### **Housing**

- Orange County identified housing as a primary need in their community. They reported that there are insufficient funds to support home modification. They also found that there is a need for a comprehensive registry of affordable housing in Orange County. Therefore, they plan to conduct a comprehensive survey of safe, affordable, accessible housing available in Orange County, as well as a review of affordable, accessible housing options available in other areas.
- Delaware County reported that they do not have any licensed assisted living programs and furthermore, recent closures have significantly reduced the number of adult home beds in the community. They also noted, like Orange County, that there is a need for more home modification services to allow individuals to stay in the home.
- The lack of assisted living beds and enriched housing programs were highlighted as gaps in long term care services in a survey conducted in Jefferson County.<sup>2</sup>
- Franklin County reported that "acceptable affordable housing" is an issue in their county.
- Schoharie County reported that their only nursing home closed in May of 2007, and as a result, many hours and resources have been spent trying to help families relocate their loved ones. The local Office for the Aging and Department of Health have spearheaded a task force, in collaboration with the county government, to explore options for nursing home care in the county. Schoharie County's Long Term Care Council will be actively involved in this task force.

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<sup>2</sup> An extensive survey was conducted by a local health organization to identify gaps in the Jefferson County long term care system. A subcommittee of the Long Term Care Advisory Council will review these findings and determine if the Long Term Care Advisory Council will adopt the findings as their gap analysis.

### **Better Coordination of Services**

- Counties have reported that there needs to be better coordination of services. NYC, through their Project Planning Team, developed an online long term care survey and invited 948 Department for the Aging (DFTA), Human Resources Administration (HRA), and State-contracted providers to take part in the survey. Approximately 30% of providers responded to the survey. Providers in NYC reported that in order to improve the long term care system in NYC, there needs to be better coordination, improved outreach and education, integration of services amongst providers and referral sources, easier access to services for consumers, increased funding, and workforce related improvements.
- Schenectady County hired a consultant who identified four strategic priorities for long term care.<sup>3</sup> These findings may be used by the Long Term Care Council for their gap analysis. The four priorities which have been identified for Schenectady County are: Information and Assistance, Service Coordination, Transportation, and Effective Collaboration. Under Service Coordination, their first goal is to “break down barriers to effective communication and service coordination between agencies that hinder and impede consumer access to services and care.” The milestone for this goal is “to identify gaps in both the service continuum and the availability of service coordination.”
- A subcommittee of Westchester’s Long Term Care Council reported that there is a dire need for “**standardized, accessible, and accountable** service coordination” in their county. The subcommittee members feel that the provision of information and resources is not enough, and that there needs to be a mechanism for individuals who need long term care services to get assistance with navigating the current systems in place.

### **ADDRESSING THE GAPS AND BARRIERS TO SERVICES**

Counties are employing different strategies to address the gaps and barriers. Several counties have formed subcommittees or workgroups from their Long Term Care Councils to allow members to focus their efforts on a particular issue. Examples of subcommittees include the following: Education and Awareness, Workforce, Transportation, Gaps and Barriers, Resource Development and Management, Care Management, and Strategic Planning. The State will follow the work and progress of these subcommittees, many of which are still in the development phases.

In an effort to highlight the gaps and barriers in their community, several counties have produced reports that will be shared with other counties, State agencies, and elected officials. These counties presented the barriers to accessing long term care services in their county, and offered solutions to addressing barriers in these papers. Several counties identified strategies to rebalance the long term care system in their documents. The strategies of one county include, but are not limited to, establishing a home modification

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<sup>3</sup> The County had hired a consultant to prioritize gaps prior to the implementation of **NY Connects**. The consultant’s report will be proposed as one of the options to consider for the Long Term Care Council gap analysis.

in the community to assist low-income older adults and individuals with disabilities, expanding the availability of adult day care services to delay and reduce the need for nursing home placements, and establishing a system to allow for electronic communication and case coordination among long term care service providers. As **NY Connects** develops and grows, the State expects more counties to share their proposed solutions to the long term care issues in their county, and take steps towards tackling those issues.

## **POSITIVE OUTCOMES OF LONG TERM CARE COUNCILS**

Counties have found the use of Long Term Care Councils an extremely effective way to cross train their members, increase awareness of services that exist in the community, and increase communication, as well as collaboration, among agencies. Long Term Care Council members are able to share information about their own agencies, services, and programs at the LTCC meetings. Moreover, several LTCCs have reported that they have invited other providers (not on the LTCC) to present on different services and programs that are also available in the county. Furthermore, because of the collaboration of the members of their Long Term Care Council, different groups and agencies report that they are now working together, and referrals to certain agencies have increased.

## **FUTURE DIRECTIONS**

The local Long Term Care Councils are well underway to making significant and positive changes to the long term care system in New York State. As NYSOFA and NYSDOH enter into a new fiscal year, they will continue to help counties enhance and strengthen their Long Term Care Councils. NYSOFA and DOH see the LTCCs as an essential mechanism to identify gaps and issues in long term care services at the local level and to problem solve around solutions. These innovative ideas will be shared with other counties for local application. Over the next year, the two agencies will also work collaboratively to:

- Help counties increase the number of consumers and caregivers serving on the Long Term Care Councils
- Continue to provide technical assistance, support, and trainings to the counties to assist them in developing and maintaining effective and productive Long Term Care Councils
- Share best practices with counties and encourage counties to learn from and support each other
- Produce updated reports on the status of the Long Term Care Councils and share information about the accomplishments of and the challenges faced by these Councils with other State agencies and legislators
- Highlight the accomplishments of the local Long Term Care Councils in a variety of venues
- Share data obtained from the local Long Term Care Councils with the Upstate and Downstate Long Term Care Advisory Councils

- Follow up on issues presented from the counties, and the Upstate and Downstate Long Term Care Advisory Councils, at the legislative level, and advocate for policies that will lead to an improved long term care system in New York State

**APPENDIX A. COUNTIES WITH ESTABLISHED GOVERNING POLICIES**

Chautauqua  
Fulton  
Niagara  
Rockland  
Schenectady  
Yates

## **APPENDIX B. METHODS FOR GAP ANALYSIS**

### **Counties that Used Surveys, Questionnaires, Focus Groups, and/or Interviews**

Jefferson <sup>4</sup>  
Lewis  
Onondaga  
Orange

### **Counties that Used Research**

Monroe

### **Counties that Sought LTCC Member Feedback**

Chemung  
Madison  
Warren-Hamilton

### **Counties that Used Gap Analysis Workshop**

Orange

### **Counties that Used Subcontractors**

Broome  
Monroe

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<sup>4</sup> A group of community leaders and stakeholders were convened by a local Assemblyman to identify gaps in their county's long term care system. An extensive survey was conducted by a local health organization and the findings presented back to the group.

## **APPENDIX C. COUNTIES THAT HAVE FORMED SUBCOMMITTEES OR WORKGROUPS**

Broome: Literature Review

Chautauqua: Community Listening Forum, County Demographics/Needs/Statistics

Cortland: Workforce

Erie: Marketing, Membership, Outcomes, and Strategic Planning

Franklin

Fulton: has separate council for consumers called the Consumer Advisory Council

Nassau: Resource Development & Management, Public Education, Health & Human Services

Niagara: Long Term Care System Analysis, Transportation

Onondaga: Gaps and Barriers, Education and Awareness, Workforce, and Caregiving

Ontario: Needs

Westchester: Advocacy, Infrastructure, Care Management, Outreach, and Education

## **APPENDIX D. COUNTIES THAT PRODUCED REPORTS/PAPERS**

Albany: *Blueprint of Recommendations for Rebalancing the Albany County Long Term Care System*

Delaware: *Issue Brief: Meeting the Needs of Delaware County's Elderly and Disabled Citizens*

Orange: *Strategic Plan and Gap Analysis for Long Term Care Services*

**APPENDIX E. COUNTIES THAT REPORTED POSITIVE OUTCOMES OF  
LTCCS**

Delaware  
Genesee  
Greene  
Lewis  
Nassau  
Schoharie  
Warren-Hamilton  
Wayne  
Westchester  
Yates