NY Connects State Long Term Care Advisory Council Meeting
Downstate Meeting Minutes
April 8, 2008

I. Welcome and Introductions – Michael Burgess – Director, NYS Office for the Aging

- Welcomed NY Connects State Long Term Care Advisory Council (LTCAC) members to the first downstate meeting. Downstate encompasses NYC, Westchester, Rockland, Nassau, and Suffolk counties.
- Emphasized the importance of community input into the implementation and development of the NY Connects program. Feedback from Council members is necessary to make the long term care system in New York more efficient and coordinated.
- LTCAC will meet three times a year.
- Informed LTCAC members that the State legislature was still working on the budget in Albany.
- Referred the Council members to the letter from NYC (Human Resources Administration and NYC Department for the Aging) in the long term care binders. In the letter, HRA and DFTA inform the State that they no longer wish to participate in the NY Connects program. Director Burgess stated that the State continues to have discussions with the NYC city agencies regarding NY Connects, and the State is committed to implementing NY Connects in NYC.
- Stated that the purpose of the first LTCAC meeting was to provide an orientation and information about the program to members, and future meetings would allow for more open discussions between members.
- Informed members that every state is required to abide by the Olmstead Decision, and that the Long Term Care Advisory Councils would advise NYSOFA on activities related to the Most Integrated Settings Coordinating Council (MISCC).

II. Presentation and Discussion of Long Term Care Reform and NY Connects: Choices for Long Term Care - Steve Fisher, Senior Health Program Analyst, Department of Health; Laurie Pferr - Executive Deputy Director, NYS Office for the Aging; Gail Koser – Assistant Director, Division of Policy, Management, and Public Information, NYS Office for the Aging

DOH Long Term Care Restructuring Update (Steve Fisher)

- NY Connects plays a significant role in the long term care restructuring, and is part of a larger statewide effort to rebalance long term care resources.
- DOH PowerPoint distributed to LTCAC members via email.
History of NY Connects and Its Role in Long Term Care Reform (Laurie Pferr)

- Overview of NY Connects, including background and history, and its role in long term care reform.
- Discussion of Olmstead Decision and the Most Integrated Settings Coordinating Council (MISCC).
- NY Connects follows the national movement to streamline access to long term care services and provide comprehensive information regarding long term care choices.

NY Connects Current Status (Gail Koser)

- Presentation of data collected during local NY Connects I & A calls
- As the meeting date, 82% of counties were providing Information and Assistance on long term care options, 91% have established Long Term Care Councils and 81% have developed a public education/outreach program.
- Future development of NY Connects: counties will continue to work on their education campaigns, strengthen collaborations and partnerships, expand and enhance resource directories, and continue to develop methods to streamline access to long term care information.

Members’ Comments

- Information included in the long term care resource directory should be updated regularly, so it remains current.
- Ensure that I & A staff make the appropriate referrals for calls received that are of an emergent nature.
- Consider having a blog on the NY Connects website to collect information on consumer comments regarding quality of services.
- Consider having a consumer rating system in the resource directory. People who have to access system may benefit from the ratings.
- Language issues should be considered in developing the statewide resource directory. NY Connects may want to partner with the NY Immigration Coalition to address some of the language issues.
- Independent Living Centers (ILCs) should be included in local efforts to streamline access to long term care information and assistance.
- Increase the capacity for the Office of Mental Health, Office of Mental Retardation and Developmental Disabilities and the Office for the Aging to work across silos to better service this population.
- Not all people can be helped through home and community based services. The LTCAC needs to also address issues regarding residential settings.
Several LTCAC members expressed their disappointment that the NYC agencies decided not to continue their participation in NY Connects, and decided to write a letter to NYC urging them to reconsider their decision.

- Ensure that the inventory of Long Term Care services and supports are accessible and comply with Section 504 of ADA.
- Conduct outreach with the medical community and create linkages with NY Connects.

III. Break for Lunch

IV. Experiences in Long Term Care

Kathleen Joyce

- Ms. Joyce became paraplegic after a severe spinal cord injury.
- She received intensive rehabilitation treatment at a nursing home following her accident, but with the help of friends and family (and the Olmstead ruling), she was able to leave the nursing home and transition back into the community.
- Ms. Joyce stated that one of her biggest challenges has been obtaining qualified home health aides, and due to high turnover rates, she is constantly training new attendants on how to care for her.
- She underscored the need for and importance of mental health services for users of the long term care system.

Muhammad Faiz

- Mr. Faiz is the father of two year-old twin boys with developmental delays.
- One of the children has a heart condition and has been admitted to the hospital several times.
- Both children have been enrolled into the Early Intervention program.
- Mr. Faiz stated that if it weren’t for the staff of the Early Intervention Program, he would have had tremendous difficulty navigating the incredibly complex long term care system.

Maggie Hoffman

- Ms. Hoffman is the mother of a young adult with special needs. She gave birth to fraternal twins 20 years ago, one of whom passed away at the age of five.
- Her surviving son has been diagnosed with multiple conditions, including Autism, Cerebral Palsy, and a seizure disorder.
- Because of his multiple diagnoses, she has had to navigate the maze of multiple agencies including the Office of Mental Retardation and Developmental Disabilities, the Office for Mental Health and the Early Intervention program.
- Ms. Hoffman indicated that caregiving responsibilities became her fulltime job.
- Ms. Hoffman feels that many programs appear to be driven by agency needs versus the needs of its constituents.
Paulette Collins

- Ms. Collins is a retired registered nurse who cared for her husband for 20 years until he passed away.
- She became disabled herself after complications from a stroke.
- Ms. Collins feels that home health aides have a very important job, but that they are severely under paid.

V. Presentation and Discussion of Local Long Term Councils

Thea Griffin (NY Connects Bureau Director)

- The purpose and role of the Local Long Term Care Councils in long term care reform were discussed.
- Discussed the diverse makeup of LTCCs including consumers, caregivers, providers, stakeholders and local government representatives.
- Local LTCCs identify the long term care system gaps and barriers and develop strategies and priorities to implement change.
- Surveys, consultants and focus groups have been developed as ways to address the barriers and gaps in service. Some counties have completed preliminary reports and white papers regarding these issues.

Diane Aparisio (Deputy Commissioner, Department of Senior Programs and Services, Westchester County)

- Reported that the first year of NY Connects was devoted to planning for the infrastructure of NY Connects with the Office for the Aging, Department of Social Services Office for the Disabled.
- Westchester decided to partner with the regional 211 system to provide Information and Assistance on long term care options.
- Westchester created three sub-committees from their Long Term Care Council to address specific issues: 1) Care Management, 2) Advocacy, and 3) Communication (Public Education).
- In addition, the Long Term Care Council works collaboratively with OMH and OMRDD and has council members that serve these populations.

Dr. Sharon Mullon (Commissioner, Department of Senior Citizen Affairs, Nassau County)

- Reported that all of health and human services are co-located in the same building, which makes it possible for collaboration and coordination. Staff received cross training from numerous agencies.
- Nassau is now focusing on building a new resource database and changing to a paperless environment. To date there are more than 500 agencies listed in this database.
- Nassau’s Long Term Care Council created an “eye catching” NY Connects brochure, which was distributed at the LTCAC meeting.
In addition to creating a brochure for NY Connects, Nassau County has also attended several speaking engagements, generated press releases and distributed flyers to spread the word about their NY Connects program.

Paula Dlouhy (Coordinator, DSS, Rockland) and Sue Belisle (Consultant for Rockland NY Connects)

- Discussed the importance of recruiting a diverse group of individuals to sit on their LTCC.
- Explained that Rockland County already had an infrastructure in place called Info Rock that allowed individuals to call in and obtain health and human services information. NY Connects and InfoRock have since merged.
- Rockland County has conducted numerous forums to teach the community about their programs.

VI. MISCC Stakeholder Group

Shirley Genn provided a brief report on the activities of the Most Integrated Settings Coordinating Council (MISCC). The MISCC meeting minutes have been included in the LTCAC binders

- Addressed the multitude of concerns regarding the quality of residential care.

VII. Public Education and Local Outreach – Greg Olsen, Director, Policy, Management, and Public Information, NYS Office for the Aging

Due to the meeting running overtime, the public education and local outreach presentation is planned for the next Advisory Council meeting.

VIII. Closing

At the end of the meeting, members were encouraged to submit suggested agenda items for the next meeting. These should be sent to Thea Griffin.

Next meetings: July 28 and October 30, 2008