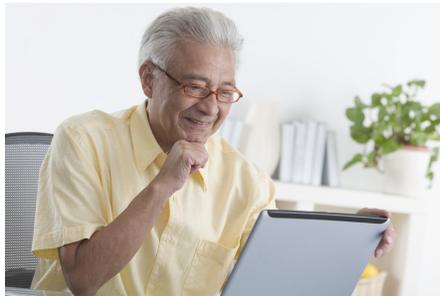


New York's Single Point of Entry for Long Term Care: A First Year Assessment of Consumer Experience With Recommendations for the Future



A report of the Long Term Care Community Coalition

by

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Background

State policymakers across the country have been considering and/or implementing single point of entry (POE) systems for long term care since the early 1990s to help consumers access the very complicated long term care system and find appropriate services. These systems, which go under different names in different states (such as "single entry point," "aging single access point" and "options for long term care") share a common, fundamental attribute: to require consumers to access long term care and supportive services through one agency or organization. Part of the impetus for developing a POE is that it can be a means by which a state fulfills its mandate under the U.S. Supreme Court's *Olmstead* decision, which requires that individuals receiving long term care under government financed programs receive the care they need in the least restrictive setting possible.¹ The expectation that a POE will result in significant cost savings (due to the more "efficient" use of services) is another major goal of POE programs, though one that is not often highly publicized.

Functionally, a POE generally provides one place for information, referral and advocacy, one place to find out about and apply for services, and one place to evaluate individuals and provide them with service recommendations. Additionally, a POE can perform a range of activities that "may include initial screening, nursing facility preadmission screening, assessment of functional capacity and service needs, financial eligibility determination, care planning, service authorization, monitoring, and periodic reassessments."²

NY State's Plan³

1. In New York State, planning for a POE got a major push when the state Health Care Reform Working Group (aka the Berger Commission) recommended the creation of a POE in its interim

¹ For more information on *Olmstead* and its relationship to POE developments please see our report, [Single Point of Entry for Long Term Care and Olmstead: An Introduction and National Perspective for Policy Makers, Consumers and Advocacy Organizations](#) (2005) available at www.ltccc.org/publications.

² Eiken, Steve and Heestand, Alexandra. "Promising Practices in Long Term Care Systems Reforms: Colorado's Single Entry Point System." December 18, 2003. Medstat Research and Policy Division, Baltimore, MD.

³ For documentation related to the genesis of NY Connects go to <http://www.nyconnects.org/about.shtml>.

report to then Governor Pataki in 2004.⁴ The New York State Office for the Aging (SOFA) and Department of Health (DOH) were given shared responsibility for implementation of the POE. In May 2006 they sent a joint request for applications⁵ to implement the POE to all NY State counties (except for those in New York City, in which the five city counties are combined as a single POE unit, where the city government was the contact point). This request sets forth an important parameter for how the POE, named NY Connects, is to be implemented in the state by any agency or organization that wins the contract: The "POE will be accessible to all individuals who may need assistance with their long term care needs regardless of age or payment source."⁶

The state's official website for the POE also provides important insights into program plans and goals:

1. "To empower individuals to make informed choices and to streamline access to long term care services and supports."
2. To furnish "comprehensive, objective information and support for individuals and their caregivers/families about home, community based and institutional long term care services and linkage to services and resources to meet their needs."
3. To provide a "comprehensive screening consisting of a preliminary evaluation of the consumer's and their caregiver's general social, medical and financial needs in order to identify available services and options."
4. To have "an on-going education and awareness campaign to educate all residents about NY Connects, the long term care services in their community and to assist consumers in preparing for their long term care needs."⁷

Another important component of the POE in New York is that each local POE is required to create a Long Term Care Council (referred to as an LTCC) to be representative of the community it serves and reflective of the ethnic and economic diversity of the service area population. In its advisory capacity, the mission of the LTCC is to analyze the long term care service delivery system, identify gaps in service accessibility and

⁴ Health Care Reform Working Group Interim Report. 2004. New York State Department of Health.

⁵ Available at

http://www.aging.state.ny.us/news/RFA/RequestforApplication_RFA_DocumentMay5,2006_1.pdf.

⁶ *Id.*

⁷ See www.nyconnects.org.

availability, as well as identify and develop strategies to rebalance existing resources. The LTCC is to use this information to problem solve at the local level and make recommendations in the development of and ongoing improvement of the POE, to advance changes in long term care access, increase community supports to meet identified needs and develop plans for how existing barriers can be overcome.

Experience To Date

New York City and every county but one (Oswego) decided to participate in NY Connects in its first year (October 2006 – September 2007).

As of Spring 2008, NY Connects programs are currently available in 44 of New York State's 57 counties⁸ and for the first quarter of significant program operation (July-September 2007), 20,691 consumer contacts were reported.⁹ The top areas of information and assistance requested were on home health care, care management, advocacy, personal care, home delivered meals, help with utility bills, and legal services. According to reports from two of the counties that made the information available, the inquiries were evenly split between consumers on Medicaid and those who pay for services privately.

New York City: A Special Case

As mentioned earlier, New York City, which consists of five counties, was considered as one locality for the development of a single point of entry. The NY City Human Resources Administration (HRA) and Department for the Aging (DFTA) were the agencies designated to develop and run the POE. LTCCC investigated the POE plans and their status in the summer of 2007 and was told that the POE was being integrated into the city's "311" resident information system. The 311 system allows people in New York City to dial 311 on their telephones and get information or help with services or report a problem.

LTCCC also inquired about what type of outreach and publicity the city was planning for the POE. We were particularly concerned about this

⁸ See http://www.nyconnects.org/dss_disclaimer.shtml.

⁹ Reported at the April 8, 2008 meeting of the State Long Term Care Advisory Council. The Council was established to advise the state on the implementation and future development of the POE. It is comprised of various stakeholders, including consumers, caregivers, advocates, providers and academics. The council is divided into two parts representing upstate and downstate, respectively, each of which has about 30-35 members.

issue, given the great diversity of New York City's population and the consequential concerns we have had since NY State first proposed a POE regarding how it would be accessible to (and useful for) people who don't speak English or for whom there might be other cultural barriers. These concerns were, in part, informed by community testimony given at the "listening sessions" that the State Office for the Aging held (under then Governor Pataki) around the state, to find out citizens' interests and concerns. In New York City, many consumers and consumer advocates voiced concerns about the barriers New Yorkers of different ethnic and racial backgrounds, gender and sexual orientation would face with accessing care through a single entry point run by the government. We were told that the crux of the planned publicity was that the DFTA commissioner would be making speeches on the POE in each of the five boroughs.

Perhaps more would have been done by HRA and DFTA to ensure that New York City's large and varied communities learn about the POE and how to best use it to access the care they need in the least restrictive setting possible. It does not appear that we will ever know, since after close to two years, the heads of HRA and DFTA sent a joint letter to the state (SOFA and DOH) informing them that the city was withdrawing from the NY Connects program.¹⁰ We anticipate that the state will be contracting with a new POE provider for the city.

LTCCC's Survey of Consumer Experience with the POE

LTCCC's concerns about how the POE was to be implemented in New York State, particularly in the city (given its diverse population), prompted us to conduct a survey of consumer experience with NY Connects.¹¹ The survey was accessible in printed form, which people could return by mail or fax to our office, or people could take the survey on-line and submit their answers electronically.

Over a four month period (November 5, 2007 through May 9, 2008) the survey was publicized via our newsletters, which carried both the printed survey and link to the on-line survey; by distributing printed copies at meetings of our coalition and at our directors' public speaking

¹⁰ Letter dated March 4, 2008 stating that the city would be focusing on the "City for All Ages" initiative that "will encompass all efforts now underway in New York City to assess age friendliness and livability of our city, and to marshal public and private resources in addressing the needs of our aging and disabled population."

¹¹ See the back of this report for a copy of the print version of the survey, which is also being conducted on-line through our website, www.ltccc.org.

engagements; and by encouraging our members to distribute the survey to their members and constituents.

Survey Respondents

We were disappointed to receive only 56 survey responses¹². Given the extent of publicity undertaken, we were surprised to find that this was one of our less participated-in surveys. We suspect that the fact that the local POEs have been launched incrementally across the state and the NYC program stalled led to low participation in the survey: there may not yet be widespread knowledge about the POE or recognition of the term "NY Connects."

Despite the small number of respondents, we were pleased to see that the respondents captured the diversity we were seeking in terms of both where in New York they were from and their professional or personal relation to the long term care system. The respondents came from twenty counties across the state – from Brooklyn to Ulster – including Madison, Manhattan, Orleans, Rockland, Cattaraugus and Suffolk.

Twenty six percent of respondents were family members or friends of long term care consumers and 14% were themselves consumers. Other respondents included long term care ombudsmen, consumer advocates, staff from the State Office for the Aging, advocates and social workers.

Survey Results

Seventy percent of respondents had heard of NY Connects. They found out about it in a variety of ways: community based organizations or agencies was the most common means of contact (42%) followed by government agencies (29%) and family or friends (13%). Respondents also reported learning about the POE through advertisements, at a library or community center, through a care planner or discharge planner, and through "Eldersource," a program which provides information and referral for older adults in Monroe County.¹³

Twenty seven percent of all respondents said they had used NY Connects, while 71% said they had not (2% were unsure whether or not they had used the POE). Approximately one third made contact via phone and another third through the internet. Other contact points (for the other third of respondents) included: in a care planning meeting, in the course of the

¹² Fifty-five via the online survey instrument and one by the mail.

¹³ For more information go to <http://www.eldersource.org/>. Eldersource is not part of the Monroe County NY Connects program, though it is a listed resource on the program's website, https://www.peerplace.com/nyportal/portal.do?county_id=26.

individual's job¹⁴ and by being invited to be part of a local long term care advisory council (the "LTCC" described earlier). The majority of respondents (80%) reported that it was easy to get the information they needed. Reasons given included: easy to use website, direct contact with county official and short turn-around time for return phone call. For the 20% who had difficulty getting the information they needed, lack of knowledge of the contact person they spoke to was most often mentioned as the reason for this problem.

Only about half (55%) of the respondents found NY Connects to be "very helpful," while a quarter (27%) found it to be "a bit helpful" and approximately a fifth (18%) said it "did not make a difference."¹⁵ The comments we received on this question indicate a wide variety of experiences. Some indicated that they found the POE to be an excellent source of information while several of those who did not find it very helpful indicated that they did not receive sufficient or appropriate information to meet their needs. One respondent's comment speaks for many in this group: "I feel it wasted my time, giving me one MORE call to make!!! Why put one more person in the process, especially considering they just recommended where I would have called anyway!!???"

The survey also gave respondents the opportunity to make general comments regarding the POE. As might be expected from the diversity of experiences (and of the respondents themselves), these comments underscored many of the key benefits of a POE system as well as some of the most serious concerns which must be addressed as the POE moves forward. Those who had a positive experience noted the ease in which they were able to get information, through both the staff and the website. One person noted that it is easy for consumers to get overwhelmed and thus "the idea of [a] single point of access is helpful." Others felt that the system "has a ways to go before it will serve the intended purpose," that more advertising is needed, as are more staff "who are knowledgeable and accessible." One respondent raised a concern that NY Connects should not "follow the footsteps of the Developmental Disabilities single point of entry process (SNAP) because they use a priority system to provide the service and as result most individuals are on waiting lists and will never actually receive the service."

¹⁴ As noted earlier a number of the correspondents were NYS agency employees and long term care ombudsmen.

¹⁵ Percentages have been rounded to the nearest whole number.

Survey Analysis

The fact that the local POEs have been launched incrementally across the state, with the NYC program stalled and many still getting off the ground, coupled with the low level of responses to our survey, means that we cannot use the survey results to draw general conclusions about the program. However, the responses do provide a number of valuable insights into how NY Connects is progressing so far, which we believe can inform future planning and implementation:

1. More public awareness is needed. Particularly since the individuals who heard about our survey are likely to be much more aware and knowledgeable of long term care issues, we would have expected to see a higher rate of awareness of NY Connects with more respondents saying that they had heard about it through publicity or advertising.
2. The internet is a good and important vehicle for providing help and information, but it can't be the only one. We were glad to see that a lot of respondents had used the website of their local NY Connects and that there were a number of positive comments about it. However, many people still do not have access to the internet or are not able to or comfortable with conducting research on the internet. While other respondents accessed NY Connect by phone, these two avenues can only be components in a broad and multi-faceted system that reaches out to and connects with people who access information differently (whether those differences are due to language, cultural or technical barriers).
3. A variety of people will use and come to rely on NY Connects, therefore the system will have to be "user-friendly" on several different levels. Since our responses came from older adults and disabled consumers, prospective consumers, caregivers and professionals, it is already clear that those accessing the POE will have a wide range of knowledge and ability to understand the different services available, how they can be accessed, etc... It is crucial that a POE be able to "speak to" and help both the consumer who is looking for services for the first time (and is probably under a great deal of stress) and the professional who might need more detailed and sophisticated information to help his or her client.
4. The POE must respond to the needs of those whose voices were not represented in the survey or in the "mainstream" community. As discussed earlier in this report, the population of New York is very diverse, and the POE must be responsive to – and accountable for – that diversity. This survey, undertaken at the onset of the program with limited resources, was only accessible to people who are

proficient in English and able to access and utilize specific community media and resources (i.e., news media and community groups that we have contact with, our websites and newsletters, etc...). Each POE must be able to serve the diverse sub-communities that make up the larger communities they are serving, whether they speak a different language (such as Spanish or Korean or Mandarin or Russian), have different cultural customs or mores, or have to overcome other obstacles stemming from racial, gender, sexual orientation or other challenges.

Recommendations

We are currently at the earliest stages of having a functioning single point of entry for long term care in New York. Nonetheless, our experience with the roll out so far and results of our survey indicate that there are several issues which will be key for the success of the POE in the future:

1. The POE will have to be seamless across the state, yet responsive to the individual communities being served. In order for NY Connects to meet some of its fundamental goals, like ensuring that NY State consumers have greater choice and flexibility in long term care, encouraging the shift to more home and community based services and more self-direction and consumer empowerment, the POEs must be up and running in every county in New York. Whatever the reasons for the POE falling apart in New York City, the result is clear: the large number of the state's long term care consumers who live in the city are not receiving the information or assistance that the POE promises to help them access services and learn how they can get the care they need in the most integrated setting possible. We hope that the state will move as quickly as possible to find a competent entity to fill this gap.
2. POE services must be truly accessible to New York's diverse communities. As mentioned earlier, New York State has a very diverse population. People from different cultures, backgrounds, and speaking different languages all represent different hurdles which the POEs will have to overcome in order to serve the state as a whole.
3. Strong monitoring and assessment are crucial to ensure that the program is really working. NY Connects could easily fall into the trap of measuring its success by increasing numbers of people who are accessing it. This in itself will not tell us about the communities that have to overcome barriers to access it and who may now be overlooked and underserved by the long term care system. As several of our survey responses indicated, many people are already

- able to find out about some or all of the services available in their communities. While it is important that people be helped to understand the range of options available to them (in terms of service procurement as well as financing), the true test of any POE will be how it has given choice and opportunity for care in less restrictive setting to those who do not have easy access to information and resources.
4. The state should undertake a major publicity campaign to ensure that people know about the POE and how to access it. This effort should ensure that people know the NY Connects name and associate it with how they can access long term care services, similar to how people know to call "911" for an emergency or "411" for information.
 5. The state should consider funding the POEs on a multi-year basis to encourage the local programs to plan their systems accordingly. One person we spoke to at a local POE said that they could not do much because they did not know what funding would be like next year or thereafter.

**SHORT QUESTIONNAIRE FOR LONG TERM CARE CONSUMERS:
IS THE SINGLE POINT OF ENTRY FOR LONG TERM CARE HELPING SENIORS &
DISABLED PEOPLE GET ACCESS TO THE CARE THEY NEED?**

New York State is launching a new program for people who need long term care, "NY Connects." The purpose of NY Connects is to provide "easy access to information and assistance for people who are exploring long term care options or who are already receiving a long term care service but would like more information."

LTCCC has developed the following short questionnaire to help us assess the experience of New York seniors & disabled people, their families and other stakeholders with NY Connects. We will use this information to inform state leaders on how well the program is working and to advocate for improvements, if necessary.

NOTE: "NY CONNECTS" IS THE OFFICIAL STATE NAME FOR THE SINGLE POINT OF ENTRY FOR LONG TERM CARE. YOUR COUNTY MIGHT USE DIFFERENT LANGUAGE. PLEASE THINK ABOUT THE LONG TERM CARE INFORMATION SERVICES PROVIDED BY YOUR COUNTY WHEN CHOOSING YOUR ANSWERS.

1. Have you heard of NY Connects (the single point of entry for long term care)? Yes No Not Sure

2. Have you used NY Connects? Yes No Not Sure

[If you answered "No" to questions 1 or 2 please skip to question # 7.]

3. How did you find out about NY Connects? Government agency
 Community based organization or agency Advertisement Friend or family Heard about at library or community center Care planner, hospital/nursing home discharge planner Other: _____

4. How did you access NY Connects? Phone Internet Other:

5. Did you find it difficult or easy to get the information you needed?

Easy Difficult Why? _____

6. Please rate how helpful NY Connects was to you:

Very helpful A bit helpful Did not make a difference Confusing
Why? _____

7. Comments? _____

8. I am a Long term care consumer Family/Friend Other: _____

9. My county of residence is: _____