Long Term Care Planning Project

Meeting 1
Aging and Long Term Care Services – Improving Coordination, Communication, and the Consumer Experience

February 4, 2019

Long Term Care Survey

In 2018, the Department of Health and the Office for the Aging (NYSOFA) released a statewide survey that gathered information on the issues faced at all levels of care by those involved in the long term care system.

The survey was designed to inform the topics for the Long Term Care Planning Project in an effort to begin analyzing and identifying the existing service gaps within New York's long term care system.

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Survey Results

- The survey was available from April 13, 2018 through July 27, 2018.

- Total Surveys Completed: 4,957

- Surveys were most often completed by:
  - Recipients of Long Term Care Services: 139
  - Informal Caregivers: 1,882
  - Neither: 2,917
    - If answered "neither," respondents were asked which type of profession they were in.

Survey Result Takeaways

- Top concerns, gaps and barriers aligned across health care professionals, CBOs/social services providers, recipients of services, and informal caregivers. Top concerns included:
  - Cost
  - Access to services
  - How to be able to age in place

- Top comments from health care providers involved:
  - Adequate staffing and low wages
  - Resources/funding
  - Rules and regulations/complexity of process

- Top comments from social services providers:
  - Adequate staffing and low wages
  - Home Care
  - Resources/funding

- Top comments from recipients of services/informal caregivers involved:
  - Cost
  - Adequate staffing and low wages
  - Family caregiver/emotional concerns

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Survey Result Takeaways

- Further discussion is needed to find the disconnect in how recipients and caregivers access information and how organizations partner with each other. According to the survey, recipients of services/informal caregivers most frequently sought non-medical support through their physician office. Professionals indicated that physician offices were 7th on their list of organizations to partner with, Community Based Organizations were the 1st.

- Almost 85% of participants associated with an organization (2,552 responded) indicated that their organization had not completed a needs assessment of older adults and/or individuals with disabilities in their service area.
  - AAAs are required to complete an assessment, further discussion needed to find the disconnect of utilizing assessments done by AAAs

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Professional Responses

- The following questions were answered by those who identified themselves as a professional in the field of aging and long term care.

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Which of the following organization type**s** are you affiliated with, if any?
If you are affiliated with more than one, check the primary type.

ANSWER CHOICES (Top 5 of 27)	RESPONSES	
Community Based Organization (CBO)	17.04%	498
Other	14.00%	409
Advocate	11.16%	326
Social Services	10.81%	316
Area Agencies on Aging (AAA)	9.34%	273

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Do you or your organization provide medical care or non-medical services to older adults and/or individuals with disabilities?

ANSWER CHOICES	RESPONSES	
Non-Medical	47.71%	1,208
Both	29.63%	858
Neither	17.58%	509
Medical	11.08%	321

Please check the top five gaps in services for older adults and/or individuals with disabilities.

ANSWER CHOICES (Top 5 out of 15)	RESPONSES*	
Information and referral resources to keep older adults and/or individuals with disabilities in their homes	59.16%	1,737
Timely access to home care services	58.17%	1,708
Lack of communication between providers, caregivers, and other agencies involved in a recipients care	56.64%	1,663
Support for caregivers	48.81%	1,433
Knowledge or understanding of the needs of older adults and/or individuals with disabilities	47.82%	1,404

*Percentages in table exceed 100% because respondents could choose more than one answer.

Gaps for the purpose of this survey are considered a disparity between current and desired services.

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Have you or your organization completed a needs assessment, gaps analysis, or other type of assessment looking at the needs of older adults and/or individuals with disabilities in your service area?

ANSWER CHOICES	RESPONSES	
No	83.07%	2,335
Yes	17.29%	486

Are there any other comments you would like to make on the long term care system?

- Comments Received: 938

- Top comments focused on the following topics:
  - Staffing and low wages
  - Resources/funding
  - Underserved areas/individuals
  - Rules & Regulations / Complexity of process
  - Cost Concerns
  - LTC Education

Caregiver and Recipient Responses

- The following questions were answered by those that identified themselves as an informal caregivers or recipient of services.

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Please check the top five concerns in relation to Long Term Care Services.

ANSWER CHOICES (Top 5 out of 18)	RESPONSES*	
Cost of services	69.91%	1,415
Worry about not being able to age at home or location of your choice	55.83%	1,130
Financial wellness	42.64%	863
Worry about losing independence	39.08%	791
Lack of resources in your community to assist with non-medical needs	36.66%	742

*Percentages in table exceed 100% because respondents could choose more than one answer.

What types of organizations do you utilize to assist with caregiving or support of non-medical services? Please check all that apply.

ANSWER CHOICES	RESPONSES*	
Physician Office	47.78%	936
Office for the Aging	33.38%	654
Home Care Agency	30.63%	600
Health Insurance Company	28.48%	558
Other (please specify)	27.11%	531

*Percentages in table exceed 100% because respondents could choose more than one answer.

Is there any other information you would like to share about the long term care system?

- Comments Received: 633

- Top comments focused on the following topics:
  - Cost Concerns
    - "Dad wants Mom home, but that would cost even more than the nursing home does."
  - Staffing and low wages
    - "It's getting quite difficult to find good home health care aids because of low wages."
  - Family Caregiver/Emotional Concerns
    - "Informal/family caregivers are undervalued ("free" to providers, not to ourselves), insufficient voice - particularly in health policy and relevant insights from observing those we care for."

Top comments (continued)

- – Accessibility
  - • "It is really hard to access the formal supports. Easier to pay out of pocket or go without if too expensive."
- – Rules & Regulations/Complexity of process
  - • New York State has done a disservice to residents by adding too many layers of "service coordinators, navigators, care coordinators, etc.) which has only caused more confusion for patients and caregivers.

Discussion Framework on Aging and Long Term Spending

- New York consistently outspends most other states with regards to Medicaid Long Term Services and Supports, accounting for 18% of total LTSS spending nationally.

- New York spent a total of approximately $26 billion in FY 2016 on Medicaid Long Term Services and Supports, a 20 percent increase from 2014 spending levels, and nearly twice as much as California - the second highest spending state.

Discussion Questions

1A. What can be done to provide a more cohesive and quality experience for care recipients?

    a. What does the care recipient need?

    b. What type of coordination/communication will provide the care recipient with the most person-centered experience?

    c. What are measures of consumer experience and satisfaction, and how can they be included in program design?

1B. What can be done to provide a more cohesive and quality experience for caregivers?

    a. What does the caregiver need?

    b. What type of coordination/communication will provide the caregiver with the most person-centered experience?

    c. What are measures of caregiver experience and satisfaction, and how can they be included in program design?

Discussion Questions

2. What are the barriers to coordination/communication across agencies, and how can it be improved?
    a. What can we do at the agency level to ensure coordination of services and information?

3. What are the barriers to communication across provider types and settings, including clinical, aging, and other human services?

4. Are there current systems to assist caregivers in specific service sectors that are working and why?

Discussion Questions

5. How do we ensure all providers, care recipients, and caregivers have the most up-to-date information without creating additional burdens? What are your ideas on how to improve this process?

6. What does an ideal communication and coordination system look like?

7. How can we better coordinate a person's care?
    a. With multiple care managers, who really takes the lead?
    b. Should a hierarchy of care management be established?
    c. What are your ideas and/or examples of how care coordinators and case managers working in different systems might collaborate to better coordinate a person's care and social supports?

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Meeting Goals

- Aspirational Goals for a Perfect System
  - To have all health systems, providers, and agencies involved in aging and long term care seamlessly communicate on every consumer, including caregivers.
  - To have every consumer understand where and how to access services before they need them.

- Achievable Goals
  - To understand where the gaps and barriers are in communication and coordination between health systems, providers, agencies, consumers, and their caregivers.
  - To develop a systematic approach to closing gaps and reducing barriers in an effective and efficient manner that does not increase burden or increase spending.

For Questions on LTCPP

Contact: ALTCteam@health.ny.gov