



**Department
of Health**



**Office for
the Aging**

Long Term Care Statewide Survey

Purpose

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.

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

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

Professional Responses

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

Question 1

- Please indicate if you are an informal caregiver (you provide care for a friend or family member but are not employed to do so; care can include assistance with meals, finance, visiting, driving to doctor's appointments) or a recipient of long term care services.

ANSWER CHOICES*	RESPONSES	
Neither	59.07%	2, 917
Informal Caregiver	38.11%	1,882
Recipient of Long Term Care Services	2.81%	139
TOTAL		4,938

* If the respondent answered as an informal caregiver or care recipient they were directed to Question 14.

* If the respondent answered "neither," they were directed to Question 2 and answered Questions 2-12.

Question 2

- Which of the following organization type 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

Question 3

- Please indicate which region(s) of New York State your organization is in.
- Department of Labor regions were used.

ANSWER CHOICES (Top 5 out of 11)	RESPONSES	
NYC (Bronx, Kings, New York, Queens, Richmond)	17.93%	517
Capital (Albany, Columbia, Greene, Saratoga, Schenectady, Rensselaer, Warren, Washington)	12.66%	365
Finger Lakes (Genessee, Livingston, Monroe, Ontario, Orleans, Seneca, Wayne, Wyoming, Yates)	12.55%	362
Hudson Valley (Ulster, Sullivan, Dutchess, Putnam, Westchester, Orange, Rockland)	12.00%	346
Long Island (Suffolk and Nassau)	9.50%	274

Question 4

- 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

Question 5

- Please check all non-medical services that you or your organization provide to older adults and/or individuals with disabilities.

ANSWER CHOICES (Top 5 out of 13)	RESPONSES*	
Advocacy	56.05%	1,534
Care Coordination/Care Management	55.02%	1,506
Home Visits	41.65%	1,140
Caregiver Support Services	33.94%	929
Transportation	29.89%	818

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

Question 6

- Please check the top five barriers to providing appropriate care to older adults and/or individuals with disabilities.

ANSWER CHOICES (Top 5 out of 19)	RESPONSES*	
Cost of services	45.91%	1,348
Lack of adequate funding for community programs	43.97%	1,291
Lack of in home care and support	42.64%	1,252
Transportation	41.96%	1,232
Support for aging in place	39.13%	1,149

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

For purposes of this survey barriers are considered something that limits or prevents people from receiving adequate services.

Question 7

- 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 in service for the purpose of this survey are considered to be a disparity between current and desired services.

Question 8

- Please check all that apply if you or your organization collaborate or partner with any organizations to help provide or assist with activities for older adults and/or individuals with disabilities.

ANSWER CHOICES (Top 5 out of 17)	RESPONSES*	
Community Based Organizations	55.78%	1,525
Home Care Agencies	50.51%	1,381
Hospitals	45.17%	1,235
Adult Day Programs	40.20%	1,099
Nursing Homes	39.76%	1,087

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

Question 9

- Have you or your organization completed a needs assessment, gap 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

Question 10

- Do you or your organization have staff with specific training on the needs of older adults and/or individuals with disabilities?

ANSWER CHOICES	RESPONSES
No	55.80% 1,591
Yes	44.34% 1,264

Questions 11 and 12

- Question 11: Are there any programs that your organization has implemented that have been successful in reducing gaps and barriers in the long term care system?
- Question 12: Are there any other comments you would like to make on the long term care system?
- Respondents were provided a text box to respond to questions 11 and 12.

Question 11 Answers

- Comments Received: over 1600

Question 12 Answers

- 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 who identified themselves as an informal caregiver or recipient of services.

Question 14

- 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.

Question 15

- 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.

Question 16

- Have you had a conversation with family or providers about advance care planning*?

ANSWER CHOICES	RESPONSES	
Yes	43.60%	876
Yes but only with immediate family such as a spouse or children	31.36%	630
No because I have not thought about it	11.75%	236
Not because this type of conversation makes me uncomfortable	6.87%	138
Other	5.03%	101
Yes but only with my physician	1.39%	28

* Advance care planning is the conversation around how you would like to receive care if you are not able to speak for yourself or diagnosed with a terminal illness.

Question 17

- If you have filled out an advance care directive, please indicate which one(s) you have filled out.

ANSWER CHOICES	RESPONSES	
Health Care Proxy	63.12%	1,068
Other (please specify)*	15.25%	258
Living Will	9.34%	158
Do-Not-Resuscitate (DNR)	7.45%	126
Medical Orders for Life Sustaining Treatment (MOLST)	4.85%	82

* This question did not allow respondents to choose more than one. Those who answered “other,” commented that they had filled out multiple advance directives.

Question 18

- Is there any other information you would like to share about the long term care system?
- Respondents were provided a text box to include comments.

Question 18 Answers

- Received 633 comments
- 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.”

Question 18 Answers (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.