

**New York State Caregiver Services Survey:**  
*NY Connects Local Long Term Care Councils'*  
*Assessment of Community*  
*Caregiver Support Services*

**Report to the New York State Family Caregiver Council**  
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## TABLE OF CONTENTS

	<b>Page</b>
<b>EXECUTIVE SUMMARY.....</b>	<b>i</b>
<b>INTRODUCTION.....</b>	<b>1</b>
<b>SURVEY METHODOLOGY.....</b>	<b>2</b>
<b>SURVEY RESPONDENT DEMOGRAPHICS.....</b>	<b>4</b>
<b>SURVEY RESULTS.....</b>	<b>6</b>
<b>RESPONDENT COMMENTS.....</b>	<b>19</b>
<b>RESPONDENTS: TOP TEN AREAS RECOMMENDED TO ADDRESS IN NEW YORK STATE.....</b>	<b>23</b>
<b>CONCLUSION.....</b>	<b>23</b>
<b>APPENDIX A: Caregiver Support Services Used in Survey Assessment Tool.....</b>	<b>25</b>

# EXECUTIVE SUMMARY

## Survey Approach

In 2008, a survey commissioned by the New York State Family Caregiver Council was developed and implemented by the Finger Lakes Geriatric Education Center (FLGEC) at the University of Rochester in conjunction with the New York State Office for the Aging (NYSOFA). The purpose was to assess caregiver services in New York State and identify ways to be more responsive to the needs of caregivers in counties across the state. The survey used a “key informant” model to collect information and identify gaps in community services for caregivers and also to capture perspectives that are representative of each community’s stakeholders (providers and consumers) in order to learn about the current state of caregiver supports and services and how they may need to be strengthened. The survey sample included a diverse group of key informant survey respondents through a representative sample of local Long Term Care Council (LTCC) members from across the state. Further, Council members identified caregivers in the community to participate in the survey. These local Councils have been established as an important component of the **NY Connects: Choices for Long Term Care (NY Connects)** programs in the 55 participating counties. Among the local Long Term Care Council membership are caregivers, service providers, recipients of services in the respondent group and county government officials. The survey included issues affecting all caregivers across the lifespan and across all disability areas.

## Survey Core Components

The following seven components formed the core of information that the survey was designed to collect:

- Information accessibility –availability of information to caregivers through **NY Connects**.
- Access to services - public outreach, hours of operation, cultural responsiveness.
- Utilization of services –waiting lists, unmet needs.
- Barriers to services –affordability, transportation, workforce issues, eligibility.
- Service gaps – areas most needed, coordination of services.
- Best practices – innovative ideas in each county.
- Policies/Regulations – barriers and priority recommendations.

## Highlights of Findings

The *New York State Caregivers Survey: NY Connects Local Long Term Care Councils’ Assessment of Community Caregiver Support Services* conveys useful insights about caregiver services as reported through a “key informant” model of evaluation and research. Further, the results of the survey provide a useful perspective on broad policy issues that need to be addressed, as well as areas for additional exploration and attention. The survey results provide data about knowledge of service availability; reported populations served; respondent awareness about information and assistance provided through **NY Connects**; respondent evaluation of services; service performance and barriers; and satisfaction ratings of services by respondents. These results offer useful information to foster discussion among local LTCC members on ways to be more responsive to the needs of caregivers in their county. Findings of particular note include:

- In general, the key informants are knowledgeable about the availability of most caregiver services in their communities. Those services with the most uncertainty are child guardianship, respite care for children of all ages, escort programs, companionship services, adult guardianship assistance, caregiver counseling and caregiver training.
- The key informants identified **NY Connects** as a valuable resource to provide information and assistance on long term care services, with a slight variance of 97 to 99 percent of participants in each region indicating that caregiver service information was available on a wide variety of caregiver services. An in-depth look at the responses identified a need to promote awareness in all regions of the state on information about transportation/escort programs, adult guardianship assistance, respite care for children of all ages, and general legal services.
- When asked about service performance and barriers to caregiver services, the issue of cultural sensitivity in service availability and delivery was identified as a barrier for most caregiver services and supports. For example, availability of bilingual staff and materials, and interpreters across nearly all caregiver services and supports were identified as gaps in the survey. This is an area where more attention and research should be directed.
- Availability of services outside usual business hours was identified as a need for several services including caregiver counseling, adult day health programs, social adult day programs, case management, home delivered meals, home rehabilitation and repairs services, information and assistance, general legal services, and transportation.
- Identified barriers to caregiver services across all categories of services were transportation, not enough staff, and inadequate funding.
- Survey respondents rated all services with moderate to high satisfaction ratings. Hospice was rated the highest on impressions of client satisfaction, and disability-related transportation had the lowest mean rating on the satisfaction scale.
- Of the top areas the State should address related to caregiver services, a subset of survey respondents identified the need for more services such as transportation, respite, in-home, and adult day care services; better support for staff including training and education, recruitment and better pay; and increased funding and more affordable services. These findings are consistent with other state and national long term care studies regarding the improvements needed to support caregivers in their caregiving role.

## **Next Steps**

The **NY Connects** LTCC in each county will be able to use the findings in this Report as they begin to identify solutions and strategies to address the identified service barriers and gaps. The relatively lower ratings, indicating lower satisfaction in service availability or delivery, for cultural sensitivity among caregiver support services and transportation will be discussed by both the local LTCCs and the New York State Family Caregiver Council to determine the best approach to address the issues.

# INTRODUCTION

## Background

**NY Connects: *Choices for Long term Care* (NY Connects)** provides 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. As part of this program, counties (through Area Agencies on Aging and Local Departments of Social Services) were each required to establish a local Long Term Care Council (LTCC), along with the provision of accurate and unbiased information and assistance on long term care services, including information to caregivers. These LTCCs are comprised of various stakeholders – consumers, caregivers, health care professionals, consumer advocates, government officials, and aging and disability providers in the community – who have knowledge and understanding of their county’s long term care system and an interest in improving the system. The purposes of the LTCC in each county are to examine and analyze the local long term care system, identify gaps and duplication in the system, and identify solutions and strategies to address the identified gaps.

## Project Objective

In 2008, a survey commissioned by the New York State Family Caregiver Council was developed and implemented by the Finger Lakes Geriatric Education Center (FLGEC) at the University of Rochester in conjunction with the New York State Office for the Aging (NYSOFA) to assess caregiver services and identify ways to be more responsive to the needs of caregivers in counties across New York State. The objective of the survey was to collect information from “key informants” about their knowledge regarding available services to caregivers in their counties in order to identify gaps in the community services for caregivers, to capture perspectives that are representative of each community’s stakeholders (providers and consumers) and to begin to problem solve. The results of the survey have helped to guide the New York State Family Caregiver Council’s formulation of broad policy recommendations.

## Caregiver Workgroup

To prepare the *New York State Caregivers Survey: NY Connects Local Long Term Care Councils’ Assessment of Community Caregiver Support Services* (the Survey), an advisory Caregiver Workgroup was established, comprised of approximately 30 members from the Family Caregiver Council, local Long Term Care Councils, **NY Connects** staff at the state and local levels, and NYSOFA. Workgroup members participated by telephone and the Internet to provide input into the development of survey items assessing caregiver services. The Workgroup helped define caregiver services, provided feedback on survey methodology, reviewed and suggested revisions to the survey draft, and conducted outreach to the local LTCC members to promote their participation in the survey.

## **SURVEY METHODOLOGY**

### **Survey Population – “Key Informant” Model through Long Term Care Councils**

This survey used a “key informant” model of evaluation and research to provide a perspective on available services to caregivers within counties. The survey sample included a diverse group of survey respondents through local Long Term Care Councils (LTCCs) including caregivers, service providers, and recipients of services. The survey was designed to provide an initial overview on caregiver services and to stimulate additional research. Members of the local LTCCs, **NY Connects** personnel, the New York City Family Caregiver Coalition, and the New York City Department for the Aging (DFTA) were asked to provide NYSOFA with contact listings so that these contacts would receive invitations from FLGEC to participate in the survey. The LTCCs were asked to reach out to caregivers and caregiver service providers in their local communities and update their membership lists to ensure all points of view were captured so that survey respondents were representative of the diversity of stakeholders in their counties.

### **Survey Distribution**

In consultation with NYSOFA and members of the Workgroup, an innovative, Internet-based electronic survey method was chosen in order to provide a quick turnaround time and to minimize respondent burden associated with a long survey. The members of the LTCCs graciously agreed to assist those respondents who did not have internet access. Initial invitations were sent via postal and electronic mail, with periodic e-mail reminders to participants. The survey itself was administered via the Internet in a secured web-based format. The approach and process were as follows:

- Individual LTCC members and New York City partners, the designated survey “key informants,” were asked to complete the survey based on their own perspective regarding the identified services.
- Reminder alerts were disseminated through **NY Connects** and LTCC leadership to “key informants.”
- A technical support toll-free number was established, and information and assistance was coordinated through FLGEC, KJT Group Survey Consultants, and NYSOFA.
- A total of 1,834 invitations were sent via postal service and e-mail.
- A total of 680 individuals responded to the invitation to complete the survey, completing all or part of the survey, representing a 37 percent response rate. Results from the 680 respondents are included in the final survey analysis.

### **Project Timeline**

The survey development took place during May and June, 2008 and the survey was implemented during July and August 2008. Analysis of the survey responses was conducted and preliminary results were reported in September, 2008.

## Survey Core Components

The following were the core dimensions upon which the survey was constructed:

- **Information accessibility** –availability of information to caregivers through **NY Connects**
- **Access to services** - public outreach, hours of operation, cultural responsiveness
- **Utilization of services** –waiting lists, unmet needs
- **Barriers to services** –affordability, transportation, workforce issues, eligibility
- **Service gaps** – areas most needed, coordination of services
- **Best practices** – innovative ideas in each county
- **Policies/Regulations** – barriers and priority recommendations

## Caregiver Services

A total of 24 caregiver services were included in the final survey. These services were chosen in consultation with NYSOFA and the Workgroup during the development phases of the project (see Appendix A for service descriptions). The individual services were broadly grouped under the following categories (in bold):

### **Direct Caregiver Support**

1. Caregiver/Care Receiver Support Groups
2. Caregiver Counseling
3. Caregiver Training

### **Facility-Based Respite**

4. Adult Day Health Programs (Medical)
5. Adult Day Programs (Social)
6. Respite care for children of all ages

### **Home and Community-Based Services**

7. Case/Care Management
8. Companionship
9. Home Delivered Meals
10. Home Health Care
11. Home Rehabilitation/Repair Services
12. Hospice
13. Information and Assistance
14. In-Home Attendants for People with Disabilities
15. Personal Emergency Response Systems
16. Private Duty Nursing
17. Personal Care

### **Legal Services**

18. Adult Guardianship Assistance
19. Advance Medical Directives
20. General Legal Services
21. Child guardianship assistance

### **Transportation**

22. Disability Related Transportation
23. Escort Programs
24. Senior Ride Programs

## **SURVEY RESPONDENT DEMOGRAPHICS**

The following demographic information provides an overview about survey respondents that helps us understand who responded to the “key informant” survey:

- **Age:** Median 51.5 years; Mean 51.15 years
- **Sex:** 88.1 percent Female; 11.9 percent Male
- **Race/Ethnicity**
  - 94 percent White
  - 1.6 percent Black
  - 1.4 percent Hispanic
  - 1.1 percent Asian or Pacific Islander
  - 1.6 percent Native American or Alaskan Native
  - 0.5 percent Other
- **Respondent was a Recipient of Caregiver Services – 17 percent**
- **Reported Personal Use of NY Connects – 38 percent**
- **Time Affiliated with Caregiver Services in their Region – 12.4 years (mean)**
- **Experience and Expertise**
  - **Caregiver status current or prior for someone with:**
    - Mental disability – current 15 percent; previous 7 percent
    - Physical disability – current 17 percent; previous 10 percent
    - Chronic medical condition – current 24 percent; previous 20 percent
    - Dementia – current 16 percent; previous 13 percent
    - Frail/elderly – current 34 percent; previous 25 percent
    - Developmental disabilities – current 11 percent; previous 5 percent
    - Never been a caregiver 29 percent
  - **Professional background**
    - Service (Agency) provider – 41 percent
    - County Area Agency on Aging – 28 percent
    - Long Term Care Council Member – 46 percent
    - Family Caregiver Council – 3 percent
    - Health Care Provider – 32 percent
    - Legal Services – 7 percent
    - Social Services/Social Work – 36 percent
    - Consumer Advocate – 20 percent
    - Local Department of Social Services – 22 percent
    - Local Department of Health – 15 percent
    - Other – 23 percent

## Analysis Grouped By Geographic Regions

Response rates for individual counties were highly variable, ranging from 4 counties with no respondents and a maximum of 42 respondents reporting from New York City. In order to maintain confidentiality and ensure adequate stability of the reported data, the analysis and data reporting was conducted using statewide totals and break downs in 9 geographic groupings based upon the Area Agencies on Aging (AAAs) caucus regions as indicated below in **Table 1**. Further, the table presents the geographic breakdown of respondents who completed the survey in its entirety (n=462).

**Table 1: Area Agencies on Aging Caucus Regions  
Regions Comprised Of The Following Counties**

<p><b>Region 1 Metropolitan New York:</b> New York City, Nassau, Suffolk, Westchester (n = 64 respondents)</p>
<p><b>Region 2 Hudson Valley:</b> Dutchess, Orange, Putnam, Rockland, Ulster (n = 39 respondents)</p>
<p><b>Region 3 Leatherstocking:</b> Columbia, Delaware, Fulton, Greene, Montgomery, Otsego, Schoharie, Sullivan (n=38 respondents)</p>
<p><b>Region 4 North Country:</b> Clinton, Essex, Franklin, St. Lawrence, St. Regis-Mohawk, Washington (n=41 respondents)</p>
<p><b>Region 5 Central NY:</b> Cayuga, Cortland, Herkimer, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego (n=49 respondents)</p>
<p><b>Region 6 Southern Tier:</b> Broome, Chemung, Chenango, Tioga, Tompkins (n=48 respondents)</p>
<p><b>Region 7 Finger Lakes:</b> Ontario, Schuyler, Seneca, Steuben, Wayne, Yates (n=67 respondents)</p>
<p><b>Region 8 Western NY:</b> Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Livingston, Monroe, Niagara, Orleans, Seneca Nation, Wyoming (n=72 respondents)</p>
<p><b>Region 9 Capital Region:</b> Albany, Rensselaer, Saratoga, Schenectady, Warren/Hamilton (n=44 respondents)</p>

## SURVEY RESULTS

The following sections of the Report provide an overview of each of the major sections addressed through the survey:

- Knowledge of Service Availability
- Reported Populations Served
- Respondent Awareness about Information and Assistance Provided through **NY Connects**
- Respondent Evaluation of Services
- Service Performance and Barriers
- Satisfaction Rating of Service by Respondents
- Respondent Demographics and Analysis Grouped by Geographic Regions
- Top Areas to Be Addressed in New York State

### **Report On Service Availability and Respondent Knowledge of Services**

In order to address the issue of whether respondents were knowledgeable about caregiver-related services available in their counties, respondents were first asked to rate their personal familiarity with each of the services offered in their county, and then to identify whether those services are available in their respective counties. For services that respondents felt they had an adequate working knowledge (rated as a threshold of “3” or higher on a seven-point scale), up to a maximum of seven services were flagged for more detailed questioning in the survey.

Respondents were asked the question below which was designed to gain feedback about their perception of local service availability, summarized in Table 2a.

**Survey Question:** *Throughout this survey, we will be asking you to evaluate caregiver services in [name of county]. Please indicate whether the following services (to your knowledge) are available in [name of county]. If you are not sure whether a service is available in your county, please select the ‘not sure’ option.*

Respondents were the most uncertain regarding the availability of “Child Guardianship Assistance,” “Respite Care for Children Of All Ages,” and “Escort Programs,” followed by “Companionship Services,” Adult Guardianship Assistance, “Caregiver Counseling,” and “Caregiver Training.”

**Table 2a: Respondents' Report of Service Availability  
Percent Not Sure if Service is Available in the County**

	<b>Not Sure if Service is Available in County %</b>
<b>Direct Caregiver Support</b>	
Caregiver/Care Receiver Support Groups	18%
Caregiver Counseling	25%
Caregiver Training	24%
<b>Facility-Based Respite</b>	
Adult Day Health Programs (Medical)**	14%
Adult Day Programs (Social)**	6%
Respite Care for Children of all Ages**	57%
<b>Home and Community-Based Services</b>	
Case/Care Management	6%
Companionship	27%
Home Delivered Meals	1.3%
Home Health Care	2%
Home Rehabilitation/Repair Services	18%
Hospice	1.5%
Information and Assistance	3.2%
In Home Attendants	20%
Private Duty Nursing	12%
Personal Care	6%
<b>Legal Services</b>	
Adult Guardianship Assistance	26%
Advance Medical Directives	17%
General Legal Services	10%
Child Guardianship Assistance	40%
<b>Transportation</b>	
Disability Related Transportation	8%
Escort Programs	49%
Senior Ride Programs	12%

*\*\*Some geographic regions had 30-40% of respondents reporting that this service was not available*

Respondents were next asked to self report their knowledge about all the services included in the list on a seven-point scale, from extremely knowledgeable (a rating of “7”) to no knowledge (a rating of “1”). Table 2b shows the average knowledge ratings of respondents for each of the listed services. This Table indicates the survey respondents were highly knowledgeable by self-report across the spectrum of service in the survey. The lowest respondent knowledge ratings were for “Child Guardianship Assistance” and “Respite Care for Children of All Ages” followed by “Adult Guardianship Assistance.” These responses closely parallel the high percentage of uncertainty in respondent perception of availability of services, as shown previously in Table 2a.

**Survey Question:** *Please indicate your level of knowledge \* regarding each of the following services currently available in [county name].*

**Table 2b: Respondents’ Knowledge Rating of Service**

<b>Caregiver Services</b>	<b>Average Respondent Knowledge Rating* (mean score)</b>
	* Rating on a 7-point scale: 7=extremely knowledgeable & 1=not at all knowledgeable. <b>All ratings of 5 &amp; over are in bold.</b>
<b>Direct Caregiver Support</b>	
Caregiver/Care Receiver Support Groups	4.82
Caregiver Counseling	4.86
Caregiver Training	4.77
<b>Facility-Based Respite</b>	
Adult Day Health Programs (Medical)	<b>5.08</b>
Adult Day Programs (Social)	<b>5.05</b>
Respite Care for Children of all Ages	3.95
<b>Home and Community-Based Services</b>	
Case/Care Management	<b>5.42</b>
Companionship	4.84
Home Delivered Meals	<b>5.58</b>
Home Health Care	<b>5.56</b>
Home Rehabilitation/Repair Services	4.61
Hospice	<b>5.51</b>
Information and Assistance	<b>5.60</b>
In Home Attendants	4.50
Personal Emergency Response Systems	<b>5.39</b>
Private Duty Nursing	4.57
Personal Care	<b>5.47</b>
<b>Legal Services</b>	
Adult Guardianship Assistance	4.06
Advance Medical Directives	<b>5.05</b>
General Legal Services	4.32
Child Guardianship Assistance	3.27

**Table 2b: Respondents' Knowledge Rating of Service, *continued***

<b>Transportation</b>	
Disability Related Transportation	4.70
Escort Programs	4.63
Senior Ride Programs	4.88

**Respondent Report on Populations Served**

Survey respondents were asked to identify the specific populations (clients/participants/patients) served by the caregiver programs and agencies in their county. Three specific groups were reported: *Children/Adolescent with disabilities or chronic illnesses*, *Adults (ages 18+) with disabilities or chronic illnesses*, and *older adults (Individuals ages 60 or older)*. The survey indicated that aside from age-specific services, all populations were identified as being recipients of the outlined caregiver services. For the older adult group, caregivers/care receivers were identified as recipients of a wide range of services, including caregiver/care receiver support groups, caregiver counseling, caregiver training, adult day health programs, and companionship. In the adults with disabilities/chronic illness group, in-home attendants, disability-related transportation, and care-case management were the most reported services in this age group. Of particular note, children were identified as recipients of respite, home care, hospice, personal attendant, private duty nursing, guardianship, and transportation services. The results of the service populations are summarized in Table 3.

**Survey Question:** *Who typically receives each of the following services currently available in [name of county]?*

**Table 3: Percent (%) of Respondents Reporting Specific Populations Served**

	<b>Children &amp; Adolescents (w/disabilities or chronic illnesses)</b>	<b>Adults (w/disabilities or chronic illnesses)</b>	<b>Older Adults (Age 60+)</b>
<b>Direct Caregiver Support</b>			
Caregiver/Care Receiver Support Groups	23%	46%	95%
Caregiver Counseling	19%	45%	94%
Caregiver Training	26%	49%	93%
<b>Facility-Based Respite</b>			
Adult Day Health Programs (Medical)	3%	42%	96%
Adult Day Programs (Social)	2%	37%	96%
Respite Care for Children of All Ages	92%	25%	16%

**Table 3: Percent (%) of Respondents Reporting Specific Populations Served, *continued***

<b>Home and Community-Based Services</b>			
Case/Care Management	62%	72%	90%
Companionship	14%	29%	97%
Home Delivered Meals	3%	21%	99%
Home Health Care	55%	71%	95%
Home Rehabilitation/Repair Services	23%	49%	95%
Hospice	39%	64%	92%
Information and Assistance	50%	71%	96%
In Home Attendants	62%	88%	70%
Personal Emergency Response Systems	12%	39%	98%
Private Duty Nursing	63%	70%	85%
Personal Care	50%	72%	94%
<b>Legal Services</b>			
Adult Guardianship Assistance	3%	61%	86%
Advance Medical Directives	15%	44%	97%
General Legal Services	31%	65%	88%
<b>Transportation</b>			
Disability Related Transportation	49%	82%	73%
Escort Programs	18%	40%	93%
Senior Ride Programs	15%	7%	99%

**Gaps in Respondents’ Awareness Regarding Services**

To identify awareness and knowledge gaps of information available through **NY Connects**, respondents were asked, for the services they were most knowledgeable about, if information and assistance was available in their county through **NY Connects**. With a slight variance of 97 to 99 percent across all regions, participants said that service information was available on a wide variety of caregiver services and supports through **NY Connects**. However, an in-depth look at the responses identified a need to promote awareness in all regions of information available through **NY Connects** for “Transportation – Escort Programs,” “Adult Guardianship Assistance,” “Respite Care for Children of all Ages,” and general “Legal Services.”

## **Service Performance and Barriers: Respondents' Ratings**

Within four major service categories, (1) Direct Caregiver Support and Facility-Based Respite; (2) Home and Community-Based Services; (3) Legal Services; and (4) Transportation, respondents were asked to rate a series of dimensions for specific services in the following content areas. The survey question, content areas, and dimensions are outlined, below:

**Survey Question:** *We are going to ask you some more detailed questions regarding some of the caregiver services that you have identified as being most knowledgeable about. Please give us your overall impression about the services, keeping in mind that in some areas there may be multiple providers available for clients to choose when accessing these services. Please indicate your level of agreement with each of the following statements related to each service category.*

### **Content Area: Access to Services**

#### **Dimensions:**

- The intake process for this service is easy to use.
- There is community awareness for this service.
- There are effective efforts in promoting this service.
- This service is offered in a variety of locations.
- Hours of operation for this service are appropriate for recipients.
- This service is responsive to the needs of long distance caregivers.
- This service is available outside of normal business hours.

### **Content Area: Cultural Sensitivity**

#### **Dimensions:**

- The needs of minority and underserved populations are being met with this service.
- There is outreach targeted towards enrolling minority and underserved populations in this service.
- Bilingual printed materials are available for this service.
- The staff providing the service is bilingual.
- Foreign language interpreters are available for this service.
- The staff is culturally sensitive to the needs of clients.

### **Content Area: Responsiveness to Sensory Impairment**

#### **Dimensions:**

- This service accommodates individuals with visual impairment.
- This service accommodates individuals with hearing impairment.

### **Content Area: Consumer Feedback**

#### **Dimension:**

- There is a mechanism for consumers to provide feedback to service providers.

### **Content Area: Barriers to Service**

#### **Dimensions:**

- Transportation is a barrier to participation in this service.
- There are long waiting lists before you can participate in (or have access to) this service.
- The eligibility criteria for this service are a barrier to participation.
- Not having enough staff to run this service is a barrier to participation.
- The service is affordable (low cost) for the majority of recipients.

- This service is adequately funded.
- Current policies and/or regulations impede the use of this service.

Respondents used a seven-point rating scale (7= Completely agree, and 1 = Completely disagree).

The results for each of the four service categories, (1) Direct Caregiver Support and Facility-Based Respite; (2) Home and Community-Based Services; (3) Legal Services; and (4) Transportation, are summarized in Tables 4 through 7. As can be seen in the series of summary tables, the services, in general, are rated moderately to highly positive (4 or higher on the 7-point scale).

### **Explanation for Tables 4 – 7 and Summary of Rating Scores**

For each table, the Survey Rating Scale is the same for each service on a seven-point scale (7= Completely agree and 1= Completely disagree).

### **Reading the Scores: Access to Services, Cultural Sensitivity, Responsiveness to Sensory Impairments, and Consumer Feedback Content Areas**

Many dimensions are rated very highly by survey respondents. In each of the four Tables that follow, dimensions rated *below a 4* are highlighted within each of these content areas, as the lower score may indicate potential issues that warrant attention on a particular dimension related to that content area for that service.

### **Reading the Scores: Barriers to Service Content Area**

For this content area within each of the four Tables, a *highlighted score (bold and italicized)* indicates a potential barrier to that service for the particular dimension highlighted. Due to question design (positive vs. negative phrasing) for each particular dimension in this content area, the respondent-identified barrier results are as follows:

Dimensions rated *at or above a 4* that would indicate a barrier to the service content area:

- Transportation is a barrier to participation in this service.
- There are long waiting lists before you can participate in (or have access to) this service.
- The eligibility criteria for this service are a barrier to participation.
- Not having enough staff to run this service is a barrier to participation.
- Current policies and/or regulations impede the use of this service.

Dimensions rated *below a 4* that would indicate a barrier to the service content area:

- The service is affordable (low cost) for the majority of recipients.
- This service is adequately funded.

### **Highlights of Results**

Access to services was, in general, rated as moderately positive. Cultural sensitivity of the services, while still in the moderately positive range, seemed to be rated lower compared to other dimensions, especially among Direct Caregiver Support and Transportation. Specific services –, hospice, information and referral, and caregiver supports, were especially highly rated. Caution should be exercised in evaluating some of the services (e.g., legal services), given the small number of respondents who felt knowledgeable enough to respond about the service. Barriers to service primarily focused on adequacy of funding and availability of staff. In general, long waiting lists and affordability were *not* identified as serious barriers.

**Table 4: Direct Caregiver Support & Facility Based Respite**

(Mean Agreement Rating on a 7-point scale) (7=completely agree and 1=completely disagree)

Items rated below a 4 are highlighted to indicate the lower score and potential barriers to that service.

	SUPPORT GROUPS	CAREGIVER COUNSELING	CAREGIVER TRAINING	ADULT DAY HEALTH PROGRAMS	ADULT DAY PROGRAM (SOCIAL)	RESPIRE CARE FOR CHILDREN
<b>Total Count</b>	107	84	58	83	87	22.00
<b>Access to Services</b>						
Intake process is easy	5.93	5.40	5.52	5.09	5.25	4.81
Community awareness	4.60	4.28	4.45	4.30	4.09	3.89
Effective promotion	5.00	4.85	4.86	4.58	4.29	4.06
Variety of locations	4.66	4.92	5.13	3.42	3.97	5.47
Hours of operation appropriate	5.27	4.97	4.94	4.80	4.75	5.60
Responsive to long distance caregivers	4.25	5.00	3.74	4.18	4.09	4.00
Availability outside business hours	5.10	3.88	4.81	2.55	2.72	6.37
<b>Cultural Sensitivity</b>						
Needs of minority and underserved populations met	4.19	4.09	4.23	4.52	4.35	4.71
Outreach towards minority and underserved populations	4.30	4.31	4.61	3.91	4.30	3.92
Staff is culturally sensitive	5.60	5.20	5.61	5.58	5.52	5.36
Bilingual materials available	3.63	3.84	4.19	3.62	3.74	4.20
Staff is bilingual	2.56	2.98	3.03	3.38	3.85	3.14
Interpreters are available	2.71	3.33	3.00	3.81	3.08	3.80
<b>Responsiveness to Sensory Impairments</b>						
Visual impairment accommodated	4.51	4.62	4.09	5.74	5.29	5.50
Hearing impairment accommodated	3.89	4.19	4.06	5.54	5.43	5.45
<b>Consumer Feedback</b>						
Mechanism for feedback	5.51	5.20	5.77	5.38	5.61	6.07

	SUPPORT GROUPS	CAREGIVER COUNSELING	CAREGIVER TRAINING	ADULT DAY HEALTH PROGRAMS	ADULT DAY PROGRAM (SOCIAL)	RESPIRE CARE FOR CHILDREN
<b>Barriers to Service* * Bolded and italicized items indicate a potential barrier to that service</b>						
Transportation	<b>4.73</b>	3.71	<b>4.81</b>	3.90	<b>5.08</b>	3.72
Long waiting lists	2.14	2.61	2.28	2.96	3.20	3.93
Eligibility criteria	2.42	2.35	2.28	3.75	3.45	<b>4.44</b>
Not enough staff	<b>4.26</b>	<b>4.38</b>	<b>4.00</b>	3.28	<b>4.07</b>	<b>4.59</b>
Policies and/or regulations impediment	2.86	2.77	2.78	<b>4.13</b>	<b>4.02</b>	3.20
Service is affordable	5.85	5.51	5.70	<b>3.49</b>	4.09	5.13
Service is adequately funded	<b>3.56</b>	<b>2.97</b>	<b>3.56</b>	<b>3.17</b>	<b>2.43</b>	<b>2.65</b>

**Table 5: Home and Community Based Services**

(Mean Agreement Rating on a 7-point scale) (7=completely agree and 1=completely disagree)

Items rated below a 4 are highlighted to indicate the lower score and potential barriers to that service.

	CASE/ CARE MANAGEMENT	COMPANIONSHIP	HOME DELIVERED MEALS	HOME HEALTH CARE	HOME REHABILITATION/ REPAIR SERVICES
<b>Total Count</b>	158	109	344	254	152
<b>Access to Services</b>					
Intake process is easy	4.85	5.26	5.97	5.09	4.77
Community awareness	4.19	4.32	6.13	5.27	4.17
Effective promotion	4.64	4.73	5.88	5.24	4.20
Variety of locations	5.09	5.00	6.15	5.95	5.09
Hours of operation appropriate	4.90	5.19	5.90	5.54	4.99
Responsive to long distance caregivers	4.77	4.73	5.81	5.36	4.68
Availability outside business hours	3.93	4.98	2.82	5.63	3.53
<b>Cultural Sensitivity</b>					
Needs of minority and underserved populations met	4.49	4.25	5.42	5.08	4.50
Outreach towards minority and underserved populations	4.20	4.71	5.05	4.57	4.33
Staff is culturally sensitive	5.51	5.36	5.67	5.58	5.05
Bilingual materials available	3.98	3.85	4.27	4.63	3.63
Staff is bilingual	2.94	3.22	3.49	3.76	3.02
Interpreters are available	4.16	3.56	3.87	4.20	3.15
<b>Responsiveness to Sensory Impairments</b>					
Visual impairment accommodated	5.21	5.26	5.98	5.96	5.50
Hearing impairment accommodated	5.16	4.92	5.96	5.95	5.43
<b>Consumer feedback</b>					
Mechanism for feedback	5.39	5.38	5.81	5.84	5.32

	CASE/ CARE MANAGEMENT	COMPANIONSHIP	HOME DELIVERED MEALS	HOME HEALTH CARE	HOME REHABILITATION/ REPAIR SERVICES
<b>Barriers to Service * <i>Bolded and italicized items indicate a potential barrier to that service</i></b>					
Transportation	3.65	<b><i>4.51</i></b>	3.21	3.63	2.78
Long waiting lists	3.69	3.71	2.74	3.49	<b><i>4.66</i></b>
Eligibility criteria	3.91	3.37	3.05	<b><i>4.34</i></b>	3.96
Not enough staff	<b><i>4.80</i></b>	<b><i>4.97</i></b>	3.93	<b><i>5.48</i></b>	<b><i>4.44</i></b>
Policies and/or regulations impediment	3.94	3.30	2.91	<b><i>4.21</i></b>	3.67
Service is affordable	5.08	4.34	6.17	4.09	4.78
Service is adequately funded	<b><i>3.42</i></b>	<b><i>2.93</i></b>	<b><i>3.27</i></b>	<b><i>3.08</i></b>	<b><i>2.82</i></b>

**Table 5: Home and Community Based Services (continued, additional services)**

(Mean Agreement Rating on a 7-point scale) (7=completely agree and 1=completely disagree)

Items rated below a 4 are highlighted to indicate the lower score and potential barriers to that service.

	HOSPICE	INFO AND ASSISTANCE	IN HOME ATTENDANTS (Disability)	PERSONAL EMERGENCY RESPONSE SYSTEMS	PRIVATE DUTY NURSING	PERSONAL CARE
<b>Total Count</b>	286	156	139	168	89	282
<b>Access to Services</b>						
Intake process is easy	5.74	5.76	4.59	6.00	4.52	4.95
Community awareness	6.01	4.76	4.57	5.71	4.57	5.16
Effective promotion	6.04	5.17	4.70	5.50	4.35	5.00
Variety of locations	6.22	5.13	5.81	5.99	5.71	6.02
Hours of operation appropriate	6.18	5.14	5.24	6.41	5.41	5.22
Responsive to long distance caregivers	6.05	5.81	5.05	6.45	5.23	5.46
Availability outside business hours	6.37	3.50	5.65	6.23	5.69	5.30
<b>Cultural Sensitivity</b>						
Needs of minority and underserved populations met	5.59	5.06	5.09	4.84	4.22	5.08
Outreach towards minority and underserved populations	5.11	5.11	4.80	4.58	3.77	4.76
Staff is culturally sensitive	6.03	5.83	5.55	5.59	5.25	5.50
Bilingual materials available	4.83	4.40	4.70	4.06	3.94	4.10
Staff is bilingual	4.37	3.49	4.31	3.49	3.76	3.73
Interpreters are available	4.98	4.53	4.49	4.30	3.54	4.25
<b>Responsiveness to Sensory Impairments</b>						
Visual impairment accommodated	4.98	4.53	4.49	4.30	3.54	4.25
Hearing impairment accommodated	6.19	5.61	5.85	5.88	6.02	6.02
<b>Consumer Feedback</b>						
Mechanism for feedback	6.15	5.40	5.80	5.85	5.82	5.91

**Table 5: Home and Community Based Services (continued, additional services), continued**

	HOSPICE	INFO AND ASSISTANCE	IN HOME ATTENDANTS (Disability)	PERSONAL EMERGENCY RESPONSE SYSTEMS	PRIVATE DUTY NURSING	PERSONAL CARE
<b>Barriers to Service* <i>Bolded and italicized items indicate a potential barrier to that service</i></b>						
Transportation	<b>6.03</b>	<b>5.49</b>	<b>5.57</b>	<b>5.83</b>	<b>5.41</b>	<b>5.72</b>
Long waiting lists	2.69	3.13	<b>4.25</b>	1.97	3.87	<b>4.05</b>
Eligibility criteria	2.56	2.15	3.38	2.61	3.13	3.90
Not enough staff	3.22	2.11	<b>4.07</b>	2.94	3.78	<b>4.00</b>
Policies and/or regulations impediment	3.84	<b>3.77</b>	3.75	3.68	3.25	3.03
Service is affordable	4.09	<b>3.68</b>	5.06	2.51	5.48	5.28
Service is adequately funded	5.75	6.33	4.63	4.55	<b>2.96</b>	4.15

**Table 6: Legal Services**

(Mean Agreement Rating on a 7-point scale) (7=completely agree and 1=completely disagree)

**Items rated below a 4 are highlighted to indicate the lower score and potential barriers to that service.**

	ADULT GUARDIANSHIP ASSISTANCE	ADVANCE MEDICAL DIRECTIVES	GENERAL LEGAL SERVICES	CHILD GUARDIANSHIP ASSISTANCE
<b>Total Count</b>	34	79	35	46
<b>Access to Services</b>				
Intake process is easy	3.14	5.49	4.39	4.14
Community awareness	3.48	4.76	3.97	3.76
Effective promotion	3.05	4.86	3.69	4.00
Variety of locations	4.45	5.78	4.14	4.82
Hours of operation appropriate	4.80	5.16	3.48	4.84
Responsive to long distance caregivers	4.37	5.38	3.47	4.10
Availability outside business hours	3.39	4.93	2.73	4.07
<b>Cultural Sensitivity</b>				
Needs of minority and underserved populations met	4.00	4.92	4.93	4.73
Outreach towards minority and underserved populations	3.53	4.76	4.74	4.36
Staff is culturally sensitive	5.63	5.63	5.11	5.29
Bilingual materials available	3.08	4.76	4.69	4.90
Staff is bilingual	3.08	3.76	4.67	4.05
Interpreters are available	4.71	4.26	4.58	4.65
<b>Responsiveness to Sensory Impairments</b>				
Visual impairment accommodated	6.06	5.27	5.85	5.58
Hearing impairment accommodated	6.05	5.41	5.67	5.48
<b>Consumer Feedback</b>				
Mechanism for feedback	4.63	5.14	4.62	4.90

**Table 6: Legal Services, continued**

	ADULT GUARDIANSHIP ASSISTANCE	ADVANCE MEDICAL DIRECTIVES	GENERAL LEGAL SERVICES	CHILD GUARDIANSHIP ASSISTANCE
<b>Barriers to Service* <i>Bolded and italicized items indicate a potential barrier to that service</i></b>				
Transportation	3.35	2.83	<b>4.43</b>	<b>4.15</b>
Long waiting lists	2.37	2.20	<b>4.05</b>	2.91
Eligibility criteria	3.79	2.55	3.45	3.63
Not enough staff	<b>4.00</b>	3.62	<b>4.76</b>	<b>4.41</b>
Policies and/or regulations impediment	3.89	2.76	3.44	3.71
Service is affordable	4.50	6.02	5.00	4.81
Service is adequately funded	<b>2.83</b>	4.28	<b>2.36</b>	<b>3.13</b>

**Table 7: Transportation**

(Mean Agreement Rating on a 7-point scale) (7=completely agree and 1=completely disagree)

**Items rated below a 4 are highlighted to indicate the lower score and potential barriers to that service.**

	DISABILITY RELATED TRANSPORTATION	ESCORT PROGRAMS	SENIOR RIDE PROGRAMS
<b>Total Count</b>	143	6	184
<b>Access to Services</b>			
Intake Process Is Easy	4.76	5.33	5.21
Community Awareness	5.03	4.50	5.14
Effective Promotion	4.75	4.25	5.02
Variety Of Locations	5.10	5.00	5.46
Hours Of Operation Appropriate	4.33	5.00	4.44
Responsive To Long Distance Caregivers	4.64	5.00	4.93
Availability Outside Business Hours	3.69	4.33	3.43
<b>Cultural Sensitivity</b>			
Needs Of Minority And Underserved Populations Met	5.06	4.50	5.19
Outreach Towards Minority And Underserved Populations	4.75	5.00	4.91
Staff Is Culturally Sensitive	5.11	5.00	5.36
Bilingual Materials Available	4.43	3.67	4.06
Staff Is Bilingual	3.77	3.00	3.60
Interpreters Are Available	4.09	3.67	3.49
<b>Responsiveness to Sensory Impairments</b>			
Visual Impairment Accommodated	5.78	5.50	5.95
Hearing Impairment Accommodated	5.66	5.25	5.86
<b>Consumer Feedback</b>			
Mechanism For Feedback	4.95	5.67	5.53

	DISABILITY RELATED TRANSPORTATION	ESCORT PROGRAMS	SENIOR RIDE PROGRAMS
<b>Barriers to Service* <i>Bolded and italicized items indicate a potential barrier to that service</i></b>			
Transportation	n/a	n/a	n/a
Long Waiting Lists	3.09	<b>5.00</b>	3.49
Eligibility Criteria	3.45	3.00	3.16
Not Enough Staff	<b>4.23</b>	<b>5.00</b>	<b>4.40</b>
Policies and/or Regulations Impediment	3.64	<b>5.33</b>	3.78
Service Is Affordable	5.00	5.67	5.75
Service Is Adequately Funded	<b>3.29</b>	<b>3.67</b>	<b>2.82</b>

### ***Satisfaction Rating of Services by Respondents***

Respondents were asked (based on their own knowledge) to rate the overall client satisfaction for each of the services on a seven point scale (7- completely satisfied and 1- not at all satisfied).

**Table 8** summarizes the mean satisfaction rating for each of the services. Generally, all services were rated with moderate to high satisfaction ratings. Hospice was rated the highest on client satisfaction, and disability-related transportation had the lowest mean rating on the satisfaction scale as reported. The results should be interpreted with some caution, as the number of respondents in each category varies and overall the mean scores had narrow standard errors (variance) indicating that most respondents indicated a narrow range of relatively high satisfaction ratings for all services that appeared in the survey.

**Survey Question:** *Of the clients utilizing (this service) in [name of county], what is your impression of their overall satisfaction with the services they receive?*

**Table 8: Satisfaction Rating of Services**

*Survey Rating Scale: Respondent rating of client satisfaction on a 7-point scale (7=completely satisfied and 1=not at all satisfied)*

<b>Service</b>	<b>Average Respondent Rating of Satisfaction (mean)</b>	<b>Total Number of Respondents</b>	<b>Respondents Not Sure (%)</b>
Caregiver/ Care Receiver Support Groups	5.44	107	12%
Caregiver Counseling	5.60	84	14%
Caregiver Training	5.64	58	19%
Adult Day Health Programs (Medical)	5.56	83	29%
Adult Day Programs (Social)	5.52	87	31%
Respite Care For Children Of All Ages	5.75	32	46%
Case/ Care Management	5.27	158	17%
Companionship	5.45	109	30%
Home Delivered Meals	5.34	344	15%
Home Health Care	5.08	254	18%
Home Rehabilitation/ Repair Services	5.05	152	36%
Hospice	6.07	286	15%
Information And Assistance	5.21	156	24%
In Home Attendants For People With Disabilities	4.93	139	30%
Personal Emergency Response Systems	5.87	168	17%
Private Duty Nursing	4.89	89	30%
Personal Care	5.03	282	21%
Adult Guardianship Assistance	4.86	34	38%
Advance Medical Directives	5.38	79	34%
General Legal Services	4.76	35	40%
Child Guardianship Assistance	4.72	46	61%
Disability Related Transportation	4.57	143	25%
Escort Programs	5.00	8	50%
Senior Ride Programs	4.97	184	17%

## **RESPONDENT COMMENTS**

### **Comments on Services**

Respondents also were asked to provide their own (free-text typed) responses as part of the survey process to highlight the following areas:

- Unmet needs/barriers (what is most needed?)
- Particular aspects that are most effective (“best practices” or innovative service designs)
- Current policies/regulations that impede the use of caregiver services

Over 3,000 comments were entered by survey participants regarding these areas. Representative samples of text excerpts are provided, below, from the respondent comments to serve in highlighting the recurrent themes in the survey responses. These comments are grouped under specific heading sections relating to the core topics that the respondents identified.

### **Comments on Caregiver Support Groups:**

“Connecting with caregivers in hospitals and transitional nursing home units would help get people connected a point of care. It is the information sharing and actual connection with caregivers that has potential to get more caregivers connected to available services. Physicians could also play a much more vital role in getting the caregivers of their patients connected with support services available in community.”

“There is a shortage of caregiver coordinators and money to fund such position(s). There is also a lack of communication between those coordinators that provide support.”

“Regular telephone contact for support. Support being offered in such a way that people access it early on, and don't wait until the crisis; perhaps by being offered as a part of regular medical care”

“Unmet needs: As a rural county, it is difficult for caregivers to drive long distances to attend. We currently have several small groups throughout the county, but could use many more if staff time available.”

“When the Alzheimer's Association recognized that a barrier to attending was someone to stay with the care receiver so the caregiver could attend, we implemented a service by which a family - with a week's notice - could arrange for a dementia care specialist through the Alzheimer's Association to stay with their loved one while they attended the (support group)”

“Lack of respite care for those caring for patients with Alzheimer's or related dementia diseases – respite is not currently available. We currently have no social day care that could assist caregivers in attending a caregiver support group. Transportation to support groups is limited at best. There are limited (if any) care receiver support groups.”

### **Comments on Caregiver Counseling:**

“The local office for the aging used to subcontract with a program to provide this counseling but decided not to fund that portion [of their programming] for this year. I believe that the quality of services offered was good, but the funding did not allow for a significant amount of education or outreach for those who might take advantage of the services. Provision of respite services also would facilitate caregivers to take advantage of the services.”

“We need to find alternate ways of advertising to the community that this service exists. Being a rural county, it is difficult to get the word out to the members of the various communities.”

### **Comments on Care/Case Management:**

“Single Point of Access for mental health case management services allows a multiagency approach to referral, screening, and prioritizing individuals for case management services.”

“Lack of Public Awareness (and) Fear of Unknown as terms and 'Care Management' is a relatively new and improved service/term used for an old service of 'Coordination of Services.' Undefined responsibilities of Care Management Provider.”

“Since DFTA’s 'transition' in case management, there are long waiting lists in parts of New York City for assessment. In some agencies, caseloads are as high as 120 per worker. While case management is not a well-publicized service, there is no point in doing outreach if caseloads are too high to be able to serve people adequately.”

“More aides (are needed) to provide the hands on service. Some of my clients go without care because there are not enough aides. Higher income for the aides and higher reimbursement of mileage would help in promoting people to want to do the hands on work with individuals throughout the North Country.”

### **Comments Home Delivered Meals:**

“To date, the county has recognized the value of the program and has made up for federal and state funding deficits in order to avoid a waiting list. Years ago, recognizing the need to serve those in the most isolated parts of the county, paid driver routes with county vehicles was implemented. This decision has made it possible to reach those in need throughout all areas of the county. We have not relied on a total volunteer service. This has been a good decision in this day of gas price increases.”

“Congregate dining in some areas allows participants an opportunity for social interaction as well as a healthy meal”

### **Comments on Home Care:**

“Continued expansion of the shared aide concept in clusters of high customers (ie: senior buildings) assists in the convenience of scheduling and also helps provide recognition and acceptance with the aides stationed at the buildings”

“Need home visits quicker upon discharge from hospitals or other institutions; need to be able to accommodate the medically complex population at home.”

“Need more workers and better pay for them. Concerns about gas prices and the impact on home care workers and reimbursement for mileage. Need medical social workers in the county health department's home health program to create a full interdisciplinary team”

“Our agency focuses on outcome based quality indicators to improve our care. Quality Indicator teams have developed several tools to use in the home such as ‘When to call our agency for conditions and concerns.’ This was developed to reduce unnecessary hospitalizations and, hopefully, to allow our nurses to triage and assess conditions and alert the MD if care is needed.”

### **Comments on State Policy and Funding:**

“...Silos in systems for example, OMRDD, OMH, OASAS, DOH, and Office of Aging. People have a multitude of problems and the service they receive depends on which agency they have been relegated to.”

“In order to better serve the clients, mutual training and understanding of the programs offered between area agency on aging (AAA) and local social services district (LDSS) staff are needed. Additionally, an assessment tool, available and to be used across programs, including care provided by LDSS, Department of Health (DOH), and the AAA, would be very beneficial.”

“Honestly what is most needed is some way to get funding made available to the hundreds of non-Medicaid seniors and disabled who truly could benefit.”

### **Comments on NY Connects:**

“**NY Connects** is a great idea to provide information on a wide variety of topics to all interested parties”

“Although information and assistance services are available to underserved populations, I do not think they take advantage of them. **NY Connects** and other government and agency services are predominantly accessed by 'middle class' people. I do not think that immigrants, non-English speakers, people living in the culture of poverty perceive this sort of help as useful. These marginalized groups rely on informal networks for both information and assistance.”

### **Comments on Transportation:**

“Affordable transportation is extremely limited. Wheelchair transport is extremely limited. Para transit is extremely difficult as well; the application process is used as a means to exclude people. Given the escalating cost to transportation, this has become even more of an issue. Those community based agencies that offer transportation are having greater difficulty in meeting the existing needs. Last but not least, the needs of those disabled in

rural communities are 100 times worse. Para transit is not at all available in these communities if there is no regular bus service within 1.25 miles of the person's residence."

### **Comments on Underserved Populations:**

"This county is sorely lacking in programs and services for young adults with mental illnesses. They are really falling through the cracks."

"[Need] more providers that deal with children. There are very few places for children, and because of that, there is a limit to space. More funding could go into in-home respite serves"

"Clients must apply to receive service coordination. It is a long and cumbersome process. All systems are so highly regulated that paperwork trumps the delivery of services."

"Many people do not know how to find good information or representation on child guardianship issues. Grandparents and other relatives are not offered representation at court and often do not know how to get an attorney. Many senior serving programs are not aware of the unique service needs of seniors who are caring for minor children or the resources available to help them."

### **Comments on Economic Issues:**

"The high cost of fuel is hampering the number of volunteers in the program. As in other parts of the country, consideration to delivering frozen meals with follow up Friendly Visitor phone calls is on the table. As the economy worsens the number of people requesting the meals is also increasing. Rural communities are finding it difficult to get and keep drivers. Obviously the most unmet need is an increase in funding."

### **Comments on Service Criteria and Eligibility:**

"The homebound rule and some of the guidelines for duration of care - these are state and federal, not local regulations and reimbursement issues!"

"If the funding source is Medicare, then the homebound rules are ridiculous restrictions to receiving the service. There seem to be more efforts to encourage nursing home care than to offer home health care."

"Age criteria. There are some disabled individuals who would benefit from the program but are not 60 years of age. At times, we refer them to the Long Term Home Health Care Program so they can get the meals."

"...many people fall through the cracks of eligibility for financial asst. to afford this service. They are underserved because they either can't pay out of pocket at all or can only afford limited assistance and not enough hours to address their health needs effectively. The other critical problem is the rural character of the county which leaves many people in outlying areas unserved because the agencies can't find staff to travel to their homes. The third issue is the unreliability of many of the core staff (home health aides). They tend to be paid the

least, and are least trained, yet they have the most daily contact and interaction with patients.”

## **RESPONDENTS: TOP TEN AREAS RECOMMENDED TO ADDRESS IN NEW YORK STATE**

Survey respondents were asked to identify the top areas that the state should address as relating to caregiver services. A total count and ranking of summary recommendations are provided in **Table 9**. Note that the counts reflect the number of individuals who ranked the issue and do not reflect a cumulative total to 100 per cent of respondents.

**Table 9: “Top 10” Recommended Areas to Address**

<b>RANK</b>	<b>Recommendation Category</b>	<b>Count</b>
1	Transportation	119
2	Respite services	115
3	Better training/education for staff	83
4	Support/help for caregivers	77
5	Recruitment of staff/aides	77
6	Home care/in-home services	70
7	Funding/adequate funding/more money	62
8	Affordable/less expensive services	42
9	Adult daycare/day services/social	38
10	Better pay/higher salaries for staff	38

## **CONCLUSION**

This survey provides a useful perspective on caregiver services as reported through a “key informant” model of evaluation and research. The survey sample included a wide-ranging group of survey respondents through the **NY Connects** LTCCs, including caregivers, service providers, and recipients of services. Of note, in this population, there is only a small proportion of the statewide respondents that were representative of racial or ethnic minority populations. This is an important consideration when thinking about the composition of individual LTCC membership. In addition, cultural sensitivity of reported services was rated comparatively lower, most especially among caregiver support services and transportation. Additional efforts may need to be focused on outreach to minority and underserved caregivers and service recipients within a community.

The purpose of the LTCCs is to examine and analyze the local long term care system, identify gaps and duplication in the system, and identify solutions and strategies to address the identified gaps. The survey results provide a tool and framework for further discussion among members to identify ways to be more responsive to the needs of caregivers in their county and address issues of access, cultural responsiveness, barriers and gaps in services.

The survey response rates for individual counties were highly variable with some counties not responding at all to the survey invitation. Although the data were sufficient in providing a statewide and regional perspective on service dimensions, the interpretation of results at the individual county level is limited. Sufficient data was available across all regions to state that, although a need for enhanced public outreach and service provider education for certain services available through **NY Connects** was identified, awareness of the overall information available through **NY Connects** is rated very high.

Access to services, in general, was rated as adequate with a moderate to high satisfaction rating for clients. Barriers to services primarily focused on adequacy of funding and availability of staff. Consistent with other research and information, the survey respondents consistently identified transportation, respite care, caregiver training, workforce recruitment, and funding/payment as the leading policy issues. These overall survey results add to the available body of knowledge about caregiver needs, the services that are useful and barriers to accessing assistance. This information will be helpful in guiding future policy recommendations to support and enhance caregiver services across New York State.

## APPENDIX A

### Caregiver Support Services Used in Survey Assessment Tool

<b>Support Service Term</b>	<b>Description</b> <i>(Defined by the Alliance for Information and Referral Systems or NYSOFA LTCCACSS Workgroup)</i>
<b>Direct Caregiver Support</b>	
Caregiver/Care Receiver Support Groups	Mutual support groups whose members are family, friends, significant others, non-familial caregivers or attendants who are caring for someone who has a temporary, chronic, life-threatening or terminal illness or disability or who is elderly and increasingly unable to provide for his or her own care. The groups meet in-person, by telephone or via the Internet; and provide emotional support, information and resources to help participants ensure their own well-being while remaining involved in the intense care of a loved one. Also included are care receiver support groups that help people who have a caregiver cope with the fact that they require care. Care receiver support groups are often offered in conjunction with caregiver support groups and are structured to allow care receivers to participate in their own group while their caregiver attends another.
Caregiver Counseling	Programs that provide emotional support, information and guidance in individual and/or group settings for family members, friends, significant others, non-familial caregivers or attendants who are caring for someone who has a serious illness or disability or who is elderly and increasingly unable to provide for his or her own care, and are feeling overwhelmed by their responsibilities and the effect that their caregiving role has had on their lives
Caregiver Training	Programs that provide training for family members and other home-based caregivers which focuses on care-related activities such as medication management, personal care and making the home environment safe and barrier-free as well as on stress management and other techniques to help the caregiver take care of him or herself.
<b>Facility Based Respite</b>	
Adult Day Health Programs	Day care centers that provide health and related services as well as care and supervision for adults who require physical rehabilitation, dementia management or other condition-specific forms of assistance on a limited but regular basis and who would be at risk of entering a skilled nursing or intermediate care facility without the support of this type of center. Ancillary services usually include meals and limited social activities.
Adult Day Programs (Social)	Programs that provide care and supervision in a protective setting for dependent adults living in the community during some portion of a 24-hour day. Services may include social and recreational activities, training that is essential for sustaining activities of daily living, hot meals, as appropriate and, if an adult day health care center, health and related services.
<b>Home and Community Based Services</b>	
Case/Care Management	Programs that develop plans for the evaluation, treatment and/or care of individuals who, because of age, illness, disability or other difficulties, need assistance in planning and arranging for services; which assess the individual's needs; coordinate the delivery of needed services; ensure that services are obtained in accordance with the case plan; and follow up and monitor progress to ensure that services are having a beneficial impact on the individual.
Companionship	Programs that provide friendship and shared activities and/or appropriate role models for individuals who suffer from lack of company, loneliness or social isolation; who need emotional support from a "buddy" to cope with a difficult life situation; who need practice conversing in English; or who lack the companionship and guidance of an adult or figure or peer role model.

Home Delivered Meals	Programs that prepare and deliver regular meals to older adults and people with disabilities who are unable to shop and/or prepare the food for themselves or travel to a site where a meal is being served.
Home Health Care	Programs that make necessary medical services available in the homes of people who are aged, ill [chronically ill/disabled] or convalescing.
Home Rehabilitation/Repair Services	Programs that provide assistance in the form of labor and supplies for people who need to make essential repairs to their homes in order to eliminate health or safety hazards and who qualify for this service on the basis of income, age or disability. Typical services include repair or replacement of broken doors and windows; correction of safety hazards such as repairs to porches, steps and sidewalks; home security improvements such as fences, security doors and smoke detectors; habitability improvements such as replacement of sinks, toilets and floor tiles; and interior and exterior painting.
Hospice	Programs that provide a full range of supportive services for terminally ill people who are in the final stages of their illnesses and for their families. Services may include medical care, pain and symptom management, home nurse visitation, case management, emotional and spiritual support, and bereavement services for the patient and members of the family. Hospice care may be provided at home, in a freestanding hospice facility, a hospice unit of a hospital or in long-term care facilities such as nursing homes. In the U.S., in order to qualify for Medicaid or Medicare reimbursement, an individual must have a life threatening illness and must be certified by their physician to have entered the last six months of life.
Information and Assistance	A service that provides individuals with information on services available within the communities; links individuals to services and opportunities that are available within the communities; and to the maximum extent practicable, establishes adequate follow-up procedures.
In Home Attendants for People with Disabilities	Programs that offer the services of individuals who have been trained to provide assistance for people who have disabilities and who need help in daily living routines in the context of their homes or when they are out in the community (including Consumer Directed care).
Personal Emergency Response Systems	Programs that provide electronic equipment which connects frail elderly individuals or people who have disabilities with participating hospitals, paramedics or other sources of emergency assistance.
Private Duty Nursing	Programs whose home health care services are provided by licensed vocational nurses and/or registered nurses who are not members of a hospital staff but are called upon to take special care of individual patients.
Personal Care	Programs that offer the services of paraprofessional aides who provide assistance with personal hygiene (bathing, grooming and mouth care), clothing care, ambulation, seating, toileting, housekeeping (changing bed linens or other chores that are essential to the individual's health and comfort), food preparation and nutritional and environmental support for recently discharged hospital patients, elderly people and people with disabilities in their own homes. Personal care may also include supervision which involves cueing, reminding, prompting or directing daily activities, as needed, but does not include medical services.
<b>Legal Services</b>	
Adult Guardianship Assistance	Programs that provide assistance for people who are in favor of or want to oppose the appointment of a guardian to protect adults from physical danger and improper treatment and/or to protect their estate from exploitation or waste when they have been found by the courts to be incapable of managing their own affairs due to Alzheimer's disease, alcoholism, mental illness or other incapacitating conditions. Adult guardianship programs are involuntary and are generally only available in states/provinces which have no arrangements for conservatorships, whose

	conservatorships are voluntary covering powers and property designated by the conservatee or whose conservatorships address only the individual's estate.
Advance Medical Directives	Programs that provide assistance for people who want to use the tools appropriate in their state/province to express their wishes regarding future medical treatment should they become incapacitated and/or to name the individual they would like to make health care decisions on their behalf.
General Legal Services	Provision of legal advice, counseling and representation by an attorney or other person acting under the supervision of an attorney. Such legal assistance may pertain to caregiver needs such as housing, eligibility for publicly assistance/sponsored entitlement programs (e.g. Medicaid), kinship/grandparents rights, mediator services, Power of Attorney, etc.
<b>Transportation</b>	
Disability Related Transportation	Programs that provide door-to-door (or curb-to-curb) transportation for purposes of shopping, banking, social events, medical appointments and similar activities for people with disabilities who need special accommodations and are unable to utilize other available means of transportation. Also included are programs that provide transportation for youngsters with disabilities who have no other means of accessing necessary specialized services and activities.
Escort Programs	Programs that accompany people who have limited mobility, cognitive impairments or other problems to specified destinations and provide assistance which may include transportation or driving services, assisting the individual to enter and leave the vehicle and buildings, carrying packages, helping the person deal with other challenges and/or providing emotional support. Escort programs may assist older adults and people with disabilities, people who have AIDS or fear they have contracted the HIV virus, and others who need emotional and/or physical support; and may have limitations regarding the types of trips that qualify for this service.
Senior Ride Programs	Programs that provide door-to-door (or curb-to-curb) transportation for purposes of medical appointments, shopping, banking, social events, and other similar activities for older adults who need special accommodations and are unable to utilize other available means of transportation.







