













Evaluating LTC Programs

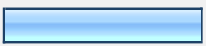
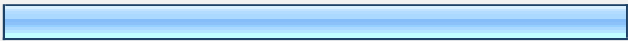

1. What type of organization do you represent?			Response Percent	Response Count
Long Term Care Ombudsman			67.3%	35
Long Term Care Consumer Group			7.7%	4
Referral or Counseling Service			1.9%	1
Professional Caregiver			3.8%	2
Other			19.2%	10
		Other (please specify)		13
		answered question		52
		skipped question		0

2. What constituency do you serve? Please choose the ONE that most closely applies to you.			Response Percent	Response Count
Aging			73.1%	38
Non-elderly disabled			15.4%	8
Mentally ill			3.8%	2
Traumatic Brain Injured			1.9%	1
People with AIDS			1.9%	1
Dementia			5.8%	3
General Population			7.7%	4
		answered question		52
		skipped question		0





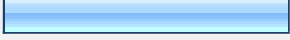
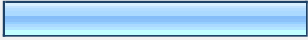
3. Please tell us how much you agree or disagree with the following statements about the long term care system.

	Strongly Agree	Moderately Agree	Moderately Disagree	Completely Disagree	Response Count
Provides the services that consumers need and want.	11.5% (6)	48.1% (25)	28.8% (15)	11.5% (6)	52
Enables people to get care in the setting they would prefer.	13.5% (7)	28.8% (15)	34.6% (18)	23.1% (12)	52
Delivers "a bang for the buck."	11.5% (6)	17.3% (9)	40.4% (21)	30.8% (16)	52
Provides access to long term care in the least restrictive setting possible for the individual.	15.4% (8)	26.9% (14)	32.7% (17)	25.0% (13)	52
Is easy for people to navigate.	11.5% (6)	17.3% (9)	32.7% (17)	38.5% (20)	52
Provides mechanisms to ensure that consumers are well informed.	13.7% (7)	23.5% (12)	41.2% (21)	21.6% (11)	51
Gives consumers choices about their care.	18.0% (9)	28.0% (14)	26.0% (13)	28.0% (14)	50
	<i>answered question</i>				52
	<i>skipped question</i>				0

4. Generally speaking, do you believe that those in your constituency who need long term care are able to get it in the least restrictive setting possible for them as individuals?

		Response Percent	Response Count
Yes		21.6%	11
No		68.6%	35
Don't know/Not sure		11.8%	6
	<i>answered question</i>		51
	<i>skipped question</i>		1

5. What are the obstacles (if any) to getting care in the least restrictive setting possible for your constituency? [Please check all that apply.]

		Response Percent	Response Count
Services are generally not available.		39.2%	20
Some services are available, but the need is greater than the availability.		74.5%	38
There is inadequate transportation for consumers to get to services (or for services to come to them).		47.1%	24
Lack of knowledge among consumers and loved ones about available services.		80.4%	41
Services are not culturally competent for some people who need them (e.g., there are people with language or cultural barriers that prevent them from accessing what is available).		31.4%	16
Other (please specify).		33.3%	17
		<i>answered question</i>	51
		<i>skipped question</i>	1

6. Following are the eight principles identified in our white paper. Please rate them according to what you think their level of importance is.

	Very Important	Somewhat Important	Not Very Important	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	94.0% (47)	6.0% (3)	0.0% (0)	50
The consumer must have the primary role in directing his or her care when able.	94.0% (47)	6.0% (3)	0.0% (0)	50
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	98.0% (49)	2.0% (1)	0.0% (0)	50
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	98.0% (49)	2.0% (1)	0.0% (0)	50
Consumers must have adequate and appropriate options of where to receive services and by whom.	92.0% (46)	8.0% (4)	0.0% (0)	50
Consumers must have culturally competent long term care services.	77.6% (38)	22.4% (11)	0.0% (0)	49
Informal caregivers must be recognized as an important part of the long term care system.	94.0% (47)	6.0% (3)	0.0% (0)	50
Formal caregivers must be recognized for their central role in providing services.	90.0% (45)	10.0% (5)	0.0% (0)	50
Other (please tell us, in brief, if you believe there is an important long term care issue that is not identified here)				9
			<i>answered question</i>	50
			<i>skipped question</i>	2

7. For each of the following INSTITUTIONAL/RESIDENTIAL LONG TERM CARE PROGRAMS that you are familiar with, please let us know if you believe it meets each guiding principle listed on the left.

Nursing Homes

	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	53.7% (22)	43.9% (18)	2.4% (1)	41
The consumer must have the primary role in directing his or her care when able.	47.6% (20)	52.4% (22)	0.0% (0)	42
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	42.5% (17)	57.5% (23)	0.0% (0)	40
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	47.5% (19)	45.0% (18)	7.5% (3)	40
Consumers must have adequate and appropriate options of where to receive services and by whom.	42.5% (17)	55.0% (22)	2.5% (1)	40
Consumers must have culturally competent long term care services.	26.3% (10)	52.6% (20)	21.1% (8)	38
Informal caregivers must be recognized as an important part of the long term care system.	55.3% (21)	44.7% (17)	0.0% (0)	38
Formal caregivers must be recognized for their central role in providing services.	61.5% (24)	35.9% (14)	2.6% (1)	39

Adult Homes

	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning	40.0% (14)	45.7% (16)	14.3% (5)	35

for the consumer's care.				
The consumer must have the primary role in directing his or her care when able.	51.4% (19)	37.8% (14)	10.8% (4)	37
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	42.9% (15)	45.7% (16)	11.4% (4)	35
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	47.2% (17)	41.7% (15)	11.1% (4)	36
Consumers must have adequate and appropriate options of where to receive services and by whom.	45.7% (16)	40.0% (14)	14.3% (5)	35
Consumers must have culturally competent long term care services.	21.2% (7)	54.5% (18)	24.2% (8)	33
Informal caregivers must be recognized as an important part of the long term care system.	45.5% (15)	45.5% (15)	9.1% (3)	33
Formal caregivers must be recognized for their central role in providing services.	52.9% (18)	32.4% (11)	14.7% (5)	34
Assisted Living Program (ALP)				
	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	40.0% (14)	28.6% (10)	31.4% (11)	35
The consumer must have the primary role in directing his or her care when able.	45.7% (16)	20.0% (7)	34.3% (12)	35
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	42.9% (15)	22.9% (8)	34.3% (12)	35

Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	41.7% (15)	30.6% (11)	27.8% (10)	36
Consumers must have adequate and appropriate options of where to receive services and by whom.	44.1% (15)	23.5% (8)	32.4% (11)	34
Consumers must have culturally competent long term care services.	21.2% (7)	33.3% (11)	45.5% (15)	33
Informal caregivers must be recognized as an important part of the long term care system.	39.4% (13)	27.3% (9)	33.3% (11)	33
Formal caregivers must be recognized for their central role in providing services.	37.5% (12)	28.1% (9)	34.4% (11)	32
Assisted Living				
	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	54.3% (19)	14.3% (5)	31.4% (11)	35
The consumer must have the primary role in directing his or her care when able.	50.0% (17)	20.6% (7)	29.4% (10)	34
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	47.1% (16)	26.5% (9)	26.5% (9)	34
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	42.9% (15)	37.1% (13)	20.0% (7)	35
Consumers must have adequate and appropriate options of where to receive services and by whom.	52.9% (18)	14.7% (5)	32.4% (11)	34

Consumers must have culturally competent long term care services.	25.0% (8)	25.0% (8)	50.0% (16)	32
Informal caregivers must be recognized as an important part of the long term care system.	50.0% (16)	21.9% (7)	28.1% (9)	32
Formal caregivers must be recognized for their central role in providing services.	46.9% (15)	25.0% (8)	28.1% (9)	32
	answered question			42
	skipped question			10

8. For each of the following COMMUNITY-BASED PROGRAMS that you are familiar with, please let us know if you believe it meets each guiding principle listed on the left.

Certified Home Health Agencies (CHHA) Services

	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	51.6% (16)	16.1% (5)	32.3% (10)	31
The consumer must have the primary role in directing his or her care when able.	50.0% (15)	20.0% (6)	30.0% (9)	30
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	43.3% (13)	30.0% (9)	26.7% (8)	30
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	60.0% (18)	16.7% (5)	23.3% (7)	30
Consumers must have adequate and appropriate options of where to receive services and by whom.	44.8% (13)	34.5% (10)	20.7% (6)	29
Consumers must have culturally competent long term care services.	31.0% (9)	31.0% (9)	37.9% (11)	29
Informal caregivers must be				

recognized as an important part of the long term care system.	65.5% (19)	17.2% (5)	17.2% (5)	29
Formal caregivers must be recognized for their central role in providing services.	70.0% (21)	10.0% (3)	20.0% (6)	30
Personal Care Assistance Program (providing (bathing, dressing, meal prep...))				
	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	48.4% (15)	12.9% (4)	38.7% (12)	31
The consumer must have the primary role in directing his or her care when able.	42.9% (12)	17.9% (5)	39.3% (11)	28
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	39.3% (11)	25.0% (7)	35.7% (10)	28
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	53.6% (15)	10.7% (3)	35.7% (10)	28
Consumers must have adequate and appropriate options of where to receive services and by whom.	32.1% (9)	32.1% (9)	35.7% (10)	28
Consumers must have culturally competent long term care services.	25.0% (7)	32.1% (9)	42.9% (12)	28
Informal caregivers must be recognized as an important part of the long term care system.	53.6% (15)	21.4% (6)	25.0% (7)	28
Formal caregivers must be recognized for their central role in providing services.	51.9% (14)	14.8% (4)	33.3% (9)	27
Consumer Directed Care Program (CDPAS)				
	Yes	No	Don't Know	Response Count

The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	51.7% (15)	0.0% (0)	48.3% (14)	29
The consumer must have the primary role in directing his or her care when able.	59.3% (16)	3.7% (1)	37.0% (10)	27
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	40.7% (11)	18.5% (5)	40.7% (11)	27
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	63.0% (17)	0.0% (0)	37.0% (10)	27
Consumers must have adequate and appropriate options of where to receive services and by whom.	48.1% (13)	14.8% (4)	37.0% (10)	27
Consumers must have culturally competent long term care services.	37.0% (10)	18.5% (5)	44.4% (12)	27
Informal caregivers must be recognized as an important part of the long term care system.	59.3% (16)	7.4% (2)	33.3% (9)	27
Formal caregivers must be recognized for their central role in providing services.	61.5% (16)	11.5% (3)	26.9% (7)	26

Expanded In Home Services for the Elderly (EISEP)

	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	50.0% (17)	2.9% (1)	47.1% (16)	34
The consumer must have the primary role in directing his or her care when able.	51.6% (16)	6.5% (2)	41.9% (13)	31
The system must also focus on understanding the whole person,				

both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	51.6% (16)	12.9% (4)	35.5% (11)	31
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	61.3% (19)	9.7% (3)	29.0% (9)	31
Consumers must have adequate and appropriate options of where to receive services and by whom.	45.2% (14)	19.4% (6)	35.5% (11)	31
Consumers must have culturally competent long term care services.	43.3% (13)	16.7% (5)	40.0% (12)	30
Informal caregivers must be recognized as an important part of the long term care system.	58.1% (18)	6.5% (2)	35.5% (11)	31
Formal caregivers must be recognized for their central role in providing services.	61.3% (19)	6.5% (2)	32.3% (10)	31
			<i>answered question</i>	35
			<i>skipped question</i>	17

9. For each of the following **MEDICAID WAIVER COMMUNITY-BASED PROGRAMS** that you are familiar with, please let us know if you believe it meets each guiding principle listed on the left.

Traumatic Brain Injury Waiver (TBI Waiver)

	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	25.0% (7)	10.7% (3)	64.3% (18)	28
The consumer must have the primary role in directing his or her care when able.	26.1% (6)	17.4% (4)	56.5% (13)	23
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	30.4% (7)	8.7% (2)	60.9% (14)	23
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	33.3% (8)	8.3% (2)	58.3% (14)	24
Consumers must have adequate and appropriate options of where to receive services and by whom.	29.2% (7)	12.5% (3)	58.3% (14)	24
Consumers must have culturally competent long term care services.	17.4% (4)	17.4% (4)	65.2% (15)	23
Informal caregivers must be recognized as an important part of the long term care system.	31.8% (7)	4.5% (1)	63.6% (14)	22
Formal caregivers must be recognized for their central role in providing services.	33.3% (8)	4.2% (1)	62.5% (15)	24

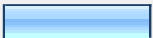
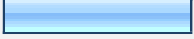


Lombardy Program/Long Term Home Health Care




	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning	20.8% (5)	12.5% (3)	66.7% (16)	24

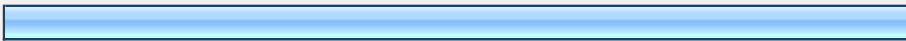
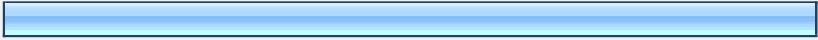
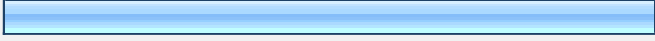
for the consumer's care.				
The consumer must have the primary role in directing his or her care when able.	21.1% (4)	21.1% (4)	57.9% (11)	19
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	21.1% (4)	10.5% (2)	68.4% (13)	19
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	35.0% (7)	10.0% (2)	55.0% (11)	20
Consumers must have adequate and appropriate options of where to receive services and by whom.	10.0% (2)	30.0% (6)	60.0% (12)	20
Consumers must have culturally competent long term care services.	20.0% (4)	20.0% (4)	60.0% (12)	20
Informal caregivers must be recognized as an important part of the long term care system.	35.0% (7)	10.0% (2)	55.0% (11)	20
Formal caregivers must be recognized for their central role in providing services.	35.0% (7)	5.0% (1)	60.0% (12)	20
Nursing Home Transition and Diversion Waiver				
	Yes	No	Don't Know	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	25.0% (7)	10.7% (3)	64.3% (18)	28
The consumer must have the primary role in directing his or her care when able.	28.0% (7)	12.0% (3)	60.0% (15)	25
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.	27.3% (6)	9.1% (2)	63.6% (14)	22

Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so safely or do not want to.	36.0% (9)	4.0% (1)	60.0% (15)	25
Consumers must have adequate and appropriate options of where to receive services and by whom.	28.0% (7)	8.0% (2)	64.0% (16)	25
Consumers must have culturally competent long term care services.	20.8% (5)	8.3% (2)	70.8% (17)	24
Informal caregivers must be recognized as an important part of the long term care system.	20.8% (5)	16.7% (4)	62.5% (15)	24
Formal caregivers must be recognized for their central role in providing services.	33.3% (8)	4.2% (1)	62.5% (15)	24
	answered question			29
	skipped question			23

10. Following are the principles from our white paper, discussed earlier. Please identify the principle that is most important to you or, if you believe that there is another principle that is more important, please state it below.

		Response Percent	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.		15.9%	7
The consumer must have the primary role in directing his or her care when able.		20.5%	9
The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences.		25.0%	11
Consumers must have the right to 'age in place' remain in their own community if they become more dependent with a decent quality of life until they can no longer do so		20.5%	9

safely or do not want to.			
Consumers must have adequate and appropriate options of where to receive services and by whom.		6.8%	3
Consumers must have culturally competent long term care services.		0.0%	0
Informal caregivers must be recognized as an important part of the long term care system.		2.3%	1
Formal caregivers must be recognized for their central role in providing services.		0.0%	0
Other (please specify)		9.1%	4
	answered question		44
	skipped question		8

11. What are the biggest challenges to realizing this principle for your constituency? [Name up to three challenges.]			
		Response Percent	Response Count
One		100.0%	39
Two		89.7%	35
Three		71.8%	28
	answered question		39
	skipped question		13

12. The central goal of this project is to develop recommendations for NY State as it restructures long term care. What would you recommend as a systemic change to overcome the challenges you listed? [Please name up to three recommendations.]

		Response Percent	Response Count
One		100.0%	35
Two		88.6%	31
Three		68.6%	24
<i>answered question</i>			35
<i>skipped question</i>			17


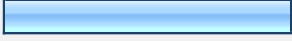
13. All responses will be kept confidential. However, if you would like to receive a copy of our final report, or other materials, please provide your contact information and indicate your preferences below.

		Response Percent	Response Count
Name:		97.0%	32
Company:		72.7%	24
Address:		90.9%	30
Address 2:		12.1%	4
City/Town:		87.9%	29
State:		97.0%	32
ZIP/Postal Code:		90.9%	30
Email Address:		100.0%	33
Phone Number:		75.8%	25
<i>answered question</i>			33
<i>skipped question</i>			19

14. Please indicate your preferences below.

	Yes	No	Response Count
We would like a copy of the final report.	86.5% (32)	13.5% (5)	37
We would like to receive monthly long term care news and action alerts.	77.1% (27)	22.9% (8)	35
	<i>answered question</i>		37
	<i>skipped question</i>		15

15. We would like to contact a small number of people who take this survey with follow-up questions. May we include your name for possible follow-up?

		Response Percent	Response Count
Yes		68.4%	26
No		31.6%	12
If you said yes, please tell us your name and email address or phone number.			18
	<i>answered question</i>		38
	<i>skipped question</i>		14