Improving Outcomes for People in Tompkins County By Strengthening the Long Term Care System

Long Term Health Care Needs Assessment – January 2010

Prepared by the Health Planning Council,
a program of the Human Services Coalition of Tompkins County, Ithaca, NY

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The Board extends its appreciation to the Committee members and staff who worked to compile and organize this information. We also thank all the health care providers and members of the public who provided information and comments for this needs assessment. This document reflects the expertise and community concern of these many people.

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We have also drawn upon the expertise of many other people, both in New York State and the United States. Many organizations have generously posted their reports and data on the web; we have incorporated excerpts of this information into our report.

Summary - *Improving Outcomes for People By Strengthening the Long Term Care System*

Many people in Tompkins County need long term care services. Need for these services is expected to increase with the aging of the population and associated debilitating diseases. At the same time, constraints in resources make improved coordination of services and reassessment of the effectiveness and the administration of services imperative.

The Long Term Care Committee of the Health Planning Council leads a coalition of organizations to improve access to needed care for our community. It is a program of the Human Services Coalition of Tompkins County. Since 2007, it has also served as the Tompkins County Long Term Care Council which was mandated as part of NY Connects, locally called Tompkins Care Connection (607-274-5222). The LTC Council has the responsibility to establish a process to periodically identify and analyze emerging community needs in the long term care service delivery system based on identified gaps, service accessibility and availability.

The Long Term Care Committee conducted this needs assessment from 2007 - 2009. We undertook several major data collection efforts including a community survey of unmet needs, relevant data from the NYS Department of Health and other sources and reports by several experts on local services.

Whenever possible, to identify trends in services, we compared current data with previous studies done by both the HPC and the County Office for the Aging. The Committee reviewed the data and contributed their own knowledge about trends, issues, and successes and gaps in the local network of services.

This assessment describes: who needs Long Term Care, how services are provided, where there are gaps in service, related issues, promising trends, and who pays for services. As this report shows, the need for skilled nursing beds has been reduced but the need for various kinds of adult home/assisted living beds has increased. Community-based services have increased, but more is needed. The community focus is changing to reducing the need for care and offering support to informal caregivers; these are the best way to reduce the cost of services as well as maintain our elderly and people with disabilities in the least restrictive setting.

The report also makes recommendations about changes needed for improvement. The HPC will work with many others to support implementation of the recommendations. We encourage community agencies, current and potential providers of services, legislators, and foundations to use these recommendations to help make informed funding and development decisions.

Long term care (LTC) is the assistance that individuals with a chronic illness or disability receive for an extended period of time to help them perform the routine activities of daily life. These may include eating, bathing, toileting, dressing, walking, and mobility as well as meal preparation, shopping, medication management, and bill paying. LTC also refers to medical services needed on an ongoing basis, from wound care up to life-sustaining treatment. This encompasses a wide array of medical, social, personal, and supportive care which may be provided in individuals' homes or community-based and residential settings.

The vast majority of Tompkins County residents do NOT need long term care services. They are able to maintain their own health or manage periodic ill health/accidents with the acute care system and rehabilitation. Even most of the 9,257 Tompkins County residents over 65 years of age live at home, in good health. Four out of five elderly residents have no limitations in mobility or self-care; less than 5% live in nursing homes.

People who do need long term health care are in three broad categories:

1) Children with special care needs, including physical, emotional and mental limitations
2) Adults ages 20 – 64, including people who had disabilities as children, were injured in accidents, or developed a debilitating illness such as multiple sclerosis, AIDS, or heart disease
3) Seniors 65 and over, including people in the above groups who have aged, ones with life-threatening illness, or gradual diminution of capacities over time

Nationally, of those needing long term care, approximately 63% are persons aged 65 and over; the remaining 37% are 64 years of age and younger. {Family Caregiving Alliance}

Estimates of Disability – Tompkins County – 2000 Census
Non-institutionalized, Civilian Persons – ages 5 and over (Does not include 350+ people who live in nursing homes)

	5 to 20	21 to 64	65 and over	Total 5 and older
With a disability	1,826 (7%)	6,831 (12%)	3,298 (38%)	11,955 (13%)

While 13% have a disability, many do not need LTC. If we mirrored national estimates, with only about 5% of the total population needing LTC, this would be 5,019 people.

Most of long term care is provided informally with people relying heavily on help from family and friends; an estimated 80% of needed home health care is provided in this way. Locally, COFA's surveys in both 1995 and 2004 found that, for people needing help with various activities of daily living, the "most common single helper was the spouse followed by combinations of other people."

In 2003, the HPC surveyed people in the county who were informal caregivers. 225 people participated in the survey, yielding a rich glimpse of the local situation. Even this limited number provided 14,726 hours of unpaid care a month. At the rate of $10/hour, the value would be $1,767,120 per year.

Community programs are a critical building block in the LTC system. They help maintain both self-care and informal care. Programs such as home-delivered meals and PERS (Personal Emergency Response System) have enabled many people to stay independent in their homes. Over the last 12 years, since the last Health Planning Council's Needs Assessment, Tompkins County has added substantially to available services; often these were identified as needs in the 1996 HPC assessment and the HPC and other community organizations have worked to promote these additions.

Paid home health care supplements informal care, community-based services and when there are no family/friends able to provide the needed help. Substantial demand for home-based services exists in Tompkins County. For example, the number of Personal Care Aide hours that Medicaid has funded has grown from 73,886 (1999) to 303,280 (2007). An estimated 75% of the care provided is given to seniors. At this time there are waiting lists for home care services often because there is not enough money in the budgets to meet all the need or there is a shortage of direct health care personnel.

The continuum of LTC facilities has expanded in the last ten years through private development and because the NYS Department of Health lifted its moratorium on assisted living programs. Between 1996 and 2009, residential capacity has increased by 294 units or beds.
Of these:

- Senior apartments increased by 222 units; 101 at Longview, 72 at Conifer Village, 46 at Brookdale Senior Living (Alterra), and 4 at Ellis Hollow (Kendal decreased by 1 unit)
- Adult homes increased by 72 beds; 36 at Brookdale Senior Living (Alterra), 24 at Kendal, 18 at Bridges, and other small changes. (Longview decreased by 17 beds)
- Nursing home beds remained stable at 555. This is scheduled to change in 2010 when Cayuga Ridge Health and Residential Community (previously Lakeside) will decrease by 160 beds; they will also be adding 90 assisted living beds and a 25-slot Adult Day Health Care Program.

The Berger Commission declared a reduced need for skilled nursing facility beds in Tompkins County and initially demanded the closure of Lakeside Nursing and Rehabilitation Facility. Community advocacy efforts resulted in a much more appropriate configuration of the facility for our county residents: 100 SNF, 80 Assisted Living Program beds and 25 Adult Day Health Care Program slots. All of these services accept Medicaid clients.

	1977	1984	1994	1996	2009	Planned Changes
Senior Citizen Apartments	418	718	823	972	1,194	+ 32
Domiciliaries	179	158	-	-		
Adult/Family Type Homes / Assisted Living	-	-	88	109	181	+ 90 (+90 proposed)
Health Related Facilities	100	140	-	-		
Skilled Nursing Facilities	292	332	520	555	555	- 160
Total	**989**	**1,348**	**1,431**	**1,636**	**1,930**	

Unmet needs were identified by the 2008 survey of Tompkins County LTC and supportive community services organizations. In order of highest need to lowest with the maximum number of people estimated to have that need in parentheses: transportation (1880), adequate workforce (1598), financing (1311), assisted living (1138), medical/dental care (813), affordable housing (647), home repair assistance (414), respite care (359), medical adult day care (133), nursing home (109), information and referral (105), hospice (61).

Because about 80% of LTC services are provided by family and friends, the largest "payer" of services is individuals through their time. Local nursing homes and home health agencies are dependent on third-party reimbursement because they do not have large endowments and the trend is toward fewer private pay patients. Long term care insurance policies are becoming more readily available to assist with nursing home and home health care payment but very few people to date have purchased this coverage. Actual dollars spent in Tompkins County on various levels of care are only available for Medicaid supported care; in 2008 this was $16,488,525. (Nationally, Medicaid pays about 50% of total LTC costs.)

A number of additional related issues were identified by local experts. These included: the importance of local assessment and coordination, shortage of health care professionals, insufficient mental health services, focus on most integrated setting, need for accessible housing, and transportation difficulties. Some promising new trends have the potential to reduce the need for LTC, improve services, and empower care recipients and their caregivers. These include: falls prevention programs, greater attention to transitions of care, transformations of nursing home care, community cooperatives, Powerful Tools for Caregivers programs, Living Healthy (chronic disease self-management) programs, advance health care planning, hospice and palliative care services.

Factors Affecting Future Needs

How long term care arrangements actually evolve depends heavily on health status and future policy choices. For example, if utilization and illness patterns current in 1997 had continued, Tompkins County would have needed an estimated 122 more skilled nursing facility beds. Obviously this did not materialize.

The aging of the baby boomers is expected to have a dramatic effect on the need for services. Fortunately the percentage of people in the older age groups who are disabled has been steadily decreasing. Older adults are staying healthier longer thus delaying the need for care.

Percentage of disability group estimates by age (National data)								
		1982	1984	1989	1994	1999	2004/5	Decrease
Age 65–74	Disabled	14.2	13.3	11.9	11.8	10.7	8.9	-37%
Age 75–84	Disabled	30.7	29.8	29.4	26.2	23.4	21.9	-29%
Age 85+	Disabled	62.1	65.9	61.4	58.5	55.6	49.7	-20%

People 85 and over are more likely to need LTC services. This demand for services will require planning and a significant growth in resources. However, we do have time to prepare. The leading edge of the baby boomers, people born in 1946, will not reach age 85 until 2031.

A recent Urban Institute report described the following key factors:

- Recent changes in family structure may have significant consequences for the availability of unpaid long-term care. Declines in birth rates, decreases in family size and increases in divorce rates, childlessness rates, and the share of people who never marry all could potentially limit the availability of unpaid long-term care by family members.
- Even in the most optimistic, low-disability scenario, which assumes that disability rates fall by 1 percent per year, the size of the population of older adults with disabilities will grow by more than 50% between 2000 and 2040.
- Although evidence points to recent health improvements at older ages, there is no guarantee that these trends will continue. Disability associated with the rising prevalence of diabetes and obesity in the younger population might offset the future decline in disability rates at older ages.

Recommendations

We, as a community, can take many steps to support changes in patterns of care and reduce or delay the need for the highest level (and highest cost) care:

1) Enhance health promotion and develop efforts to reduce or delay the need for long term care services.
2) Strengthen services that enable individuals with long term care needs to remain at home.
3) Provide support services for informal caregivers.
4) Give people information they need about options so they can make informed choices and advocate for their own needs.
5) Increase the supply of direct health care workers.
6) Expand the options for a continuum of care, including assisted living for people of all income brackets.
7) Enhance the ability of the current system to provide comprehensive care.
8) Promote new options for financing and providing quality health care.

Creating Solutions Together

The Recommendations in this report further detail steps our community can take to provide needed services in a caring, cost-effective way. The Health Planning Council will work with many others to support implementation of the recommendations. We encourage community agencies, current and potential providers of services, legislators, and foundations to use these recommendations to help make informed funding and development decisions.

For more information, to share your perspective, or to become involved in strengthening our LTC system, please contact Betty Falcão, 607-273-8686 or bfalcao@hsctc.org. The full 70-page report can be accesses on www.hsctc.org, click on health.

Long Term Health Care Needs Assessment Recommendations

These recommendations detail steps our community can take to provide needed services in a caring, cost-effective way. The Health Planning Council will work with many others to support implementation of the recommendations. We encourage community agencies, current and potential providers of services, legislators, and foundations to use these recommendations to help make informed funding and development decisions.

Improving Outcomes for People By Strengthening the Long Term Care System

1. Enhance health promotion and develop efforts to reduce or delay the need for long term care (LTC) services.

Advocate for more insurance coverage for 1) health education programs and 2) chronic disease management programs.

Encourage appropriate agencies to provide programs that support behavioral changes to increase wellness (ex. Living Healthy Workshop).

Support evidence-based programs which contribute to reducing the incidence of falls.

Support traffic-safety programs to reduce the long-term medical consequences of motor vehicle accidents.

Promote programs which help reduce the incidence of HIV and AIDS, including the needle exchange program.

Encourage government funding programs (Medicare, Medicaid, Veterans Administration, Children with Special Needs) to be flexible with resources and emphasize prevention and self-care programs.

Support the use of assistive equipment and technology, such as walkers and bath benches, to maximize safety and independence.

Increase the awareness of healthcare providers of the availability of chronic disease self-management workshops and other supportive programs so that they may refer their clients to these.

2. Strengthen services that enable individuals with LTC needs to remain at home.

Support programs which give people tools to maintain self-sufficiency (ex. Lifelong's Check It!).

Encourage the development of neighborhood and community centered programs.

Create more affordable and adequate social and medical adult day care services.

Help low-income individuals with long term care needs with home repairs and home modifications if needed for accessibility.

Support current efforts to recruit and train additional volunteer senior companions and friendly visitors to provide respite and other services (ex. County Office for the Aging's Project Care program).

Publicize the loan closets with their supply of medical equipment for people to borrow and Finger Lakes Independence Center's "Try It" room for more specialized needs.

Advocate for adequate funds for services such as home-delivered meals and EISEP (Expanded In-Home Services for the Elderly Program) which enable individuals with long term care needs to remain at home.

Increase the amount of services that offer in-home psychiatric care and psychiatric medication management.

Develop support services for individuals with LTC needs who suffer from depression.

Expand and improve existing transportation options to include services on evenings and weekends with relatively short notice that will take clients outside of Tompkins County and that will offer transportation to and from food pantry services and for other non-medical needs.

Increase the awareness of individuals about available transportation services; also increase awareness of local agencies so they can refer clients efficiently.

3. Provide support services for informal caregivers.

Maintain and expand caregiver services needed to support family and friends who typically provide almost 80% of the care needed. These tools include – COFA's support groups, caregiver respite, newsletter, Powerful Tools for Caregivers and individual counseling and support services, and Next Steps in Care; and Family and Children's Services caregiver counseling and caregiver respite programs.

Maintain and expand support for parents who have children with special needs (from Tompkins County Health Department, Franziska Racker Center, school systems, etc.).

Offer workshops for caregivers to educate them on various health problems (ex. Alzheimer's, dementia, Parkinson's, palliative care) and to train caregivers on basic care needs (ex. bathing and lifting as well as what signs and symptoms to look for in the care receiver to report to doctors).

Support grief counseling for caregivers (ex. Hospicare's program).

Provide information to employers for use by their employees who are also caregivers.

Support and expand the respite care network.

4. Give people information they need about options so they can make informed choices and advocate for their own needs.

Help clients get proper referrals to available services, help individuals with long term care needs understand what options for services are available and further, help them find the services to access them, (ex. Tompkins Care Connection, 607-274-5222).

Make it easier for long distance care givers to locate agencies and services for their loved ones in Tompkins County. Help TC residents who are caring for someone in another locality identify where to go for support and information.

Encourage people to review and decide about advance directives (such as health care proxy, do not resuscitate orders, living will, MOLST) before they need care (ex. Sharing Your Wishes).

Help patients find the tools to weigh the benefits and burdens of medical treatment options; including, fiscal implications as well as communicating with their medical providers and families.

Publicize the existence of translators to help people understand their choices for care and cultivate cultural competency in health care professionals

Publicize the existence of ways to know of available services: COFA's consumer guides to services, Tompkins Care Connection web site (www.tompkins-co.org/cofa/TompkinsCareConnection.htm).

5. Increase the supply of direct health care workers.

Expand the recruitment, training and retention of personal care aides, home health aides and certified nursing assistants. Increase public recognition of the importance of these critical workers.

Advocate for adequate pay and benefits for direct health care workers.

Encourage local agencies to participate in workforce training.

Advocate with workforce development and other partners to keep direct care worker issues as a priority.

6. Expand the options for a continuum of care, including assisted living for people of all income brackets.

Encourage the development of the assisted living level of care in Tompkins County by working to streamline regulations.

Promote transitions to least restrictive and most integrated settings to allow for aging in place.

Maintain and improve housing stock with universal design making livable communities.

Encourage the development of programs which provide residential care for chronically mentally ill LTC patients.

Advocate the expanded reimbursement through governmental programs, private insurance and increased use of sliding fee scales to cover a continuum of services in the community.

Support approaches which make care in facilities more homelike and inviting and which healp address feelings of loneliness, helplessness and boredom (ex. Eden Alternative).

7. Enhance the ability of the current system to provide comprehensive care.

Improve the communication between agencies and service providers. Strengthen these collaborations to create a seamless, client-centered system.

Support efforts to improve discharge planning and coordination during care transitions; between any two levels of care, moving from children's services to those for adults, for people with disabilities (including mental health conditions) as they age.

Support community organizations in their services to HIV+ individuals, and mental health and developmentally disabled persons.

Provide support for younger individuals with long term care needs.

Find ways to provide more resources to the rural areas of Tompkins County.

Encourage training of health care professionals in geriatrics.

Advocate for coordinated services for the mentally ill, those suffering from substance abuse, and those suffering from elder abuse.

Maintain strong local assessment and coordination systems.

8. Promote new options for financing and providing quality health care.

Advocate for comprehensive health insurance that is affordable and includes good dental benefits, or improve the options for financing needed services.

Enhance consumer fiscal responsibility for LTC expenses through education and advance planning.

Advocate that elected officials at local, state and federal levels make LTC needs and disparities a priority.

Purpose of Assessment

Many people in Tompkins County need long term care services. Need for these services is expected to increase with the aging of the population and associated debilitating diseases. At the same time, constraints in resources make improved coordination of services and reassessment of the effectiveness and the administration of services imperative.

The Long Term Care Committee of the Health Planning Council, a program of the Human Services Coalition of Tompkins County, leads a coalition of organizations to improve access to needed care for our community. Since 2007, it has also served as the Tompkins County Long Term Care Council which was mandated as part of NY Connects. Locally called Tompkins Care Connection, this program provides information and referral, assessment and case management services. The LTC Council has the responsibility to establish a process to periodically identify and analyze emerging community needs in the long term care service delivery system based on identified gaps, service accessibility and availability.

Needs Assessment Process and Sources of Data

The Long Term Care Committee of the Health Planning Council conducted the needs assessment from 2007 - 2009. We undertook several major data collection efforts:

- Community survey of unmet needs in the long term care system
- Relevant data from the NYS Department of Health and other web-based sources
- Reports by several experts on local services

Whenever possible we also compared current data with previous studies to identify trends in services. Previous studies have been done by both the Health Planning Council and the County Office for the Aging. The Committee reviewed the data and contributed their own knowledge about trends, issues, successes and gaps in the local network of services. This assessment describes:

A. Who needs Long Term Care?

B. How are services provided?

1. Family and friends
2. Supportive community services
3. Home health care agencies
4. Residential care facilities

C. Where are the gaps in services?

D. Related issues and promising trends

E. How are services paid for and how much money is used?

F. Factors affecting future need for services

The report also makes recommendations about changes needed for improvement. The Health Planning Council will work with many others to support implementation of the recommendations. We encourage community agencies, current and potential providers of services, legislators, and foundations to use these recommendations to help make informed funding and development decisions.

Definition of Long Term Care

Long term care is the assistance that individuals with a chronic illness or disability receive for an extended period of time to help them perform the routine activities of daily life. It also refers to medical services needed on an ongoing basis, from wound care up to life-sustaining treatment. Long term care encompasses a wide array of medical, social, personal, and supportive care. Such services may be provided in individuals' homes or other community-based and residential settings.

Many of the care assessment tools describe the help that is needed as:

ADL's (Activities of Daily Living) include eating, bathing, toileting, dressing and mobility.
IADL's (Instrumental Activities of Daily Living) include meal preparation, shopping, medication management, and bill paying.

A presentation by the County Office for the Aging on Powerful Tools for Caregivers further notes:

Family caregiving involves so much more than helping with these activities of daily living. It may also include other CARE MANAGEMENT tasks like:

- Assistance with advanced planning: medical directives, legal and financial planning, etc.
- Help coordinating physician appointments and scheduling all kinds of other services
- Arranging for home modifications for safety and accessibility
- Difficult communications and difficult decision-making: when to stop driving, when to hire paid aide service, when to move to residential care

...and when a loved one has dementia additional caregiving challenges, such as: difficulties with communication, managing difficult behaviors and planning activities for the person with dementia

Who needs Long Term Care?

The vast majority of Tompkins County residents do NOT need long term care services.

They are able to maintain their own health or manage periodic ill health/accidents with the acute care system and rehabilitation. Even most of the 9,257 Tompkins County residents over 65 years of age live at home, in good health. Four out of five elderly residents have no limitations in mobility or self-care; less than 5% live in nursing homes.

People needing long term health care are in three broad categories:

1. Children with special care needs, including physical, emotional and mental limitations.
2. Adults ages 20 – 64, including people who had disabilities as children, were injured in accidents, or developed a debilitating illness such as multiple sclerosis, AIDS, or heart disease.
3. Seniors 65 and over, including people in the above groups who have aged, ones with life-threatening illness, or gradual diminution of capacities over time.

Nationally, of people in need of long term care, approximately 63% are persons aged 65 and older; the remaining 37% are 64 years of age and younger. {Family Caregiving Alliance}

Long term care is something that most people will experience at some point in their life. For people 65 and older, the lifetime probability of becoming disabled in at least two activities of daily living or of being cognitively impaired is 68%. {Family Caregiving Alliance}

Only about 10% of people die suddenly; most die after a chronic, life-threatening illness.

Although all ages can need long term care, older people typically need more care than younger people. The 2000 figures in the tables below are from the Census Bureau.

Estimates of Disability – Tompkins County – 2000 Census
Non-institutionalized, Civilian Persons – ages 5 and over
(Does not include about 350 people who live in nursing homes)

	5 to 20		21 to 64		65 and over		Total 5 and older	
	#	%	#	%	#	%	#	%
With a disability	1,826	(7%)	6,831	(12%)	3,298	(38%)	11,955	(13%)
No disability	25,475	(93%)	48,327	(88%)	5,474	(62%)	79,276	(87%)

Per the 2000 Census most of our residents with disabilities live outside the urban center of our county thus requiring that services be provided in more rural geographic sectors as well as population centers.

While 13.1% of people in Tompkins County have a disability, many of these individuals do not need LTC. Per national estimates, if only about 5% of the total population need LTC this would be 5,019 people.

Children

The Federal government has adopted the following definition: Children with Special Care Needs are those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Children who meet this definition have a wide variety of conditions and illnesses. A small percentage is permanently dependent or disabled. The vast majority will grow up to lead productive lives. (Source: Tompkins County Health Department 2008 Annual Report)

The Tompkins County Health Department partners with the Franziska Racker Centers, the school districts and others to provide services to these children. The Early Intervention Program received referrals concerning 270 children in 2008. In the Preschool Special Education program 371 children received services in the 2007-2008 school year. The Racker Centers serves 90 children under 20 with intellectual and developmental disabilities, 76 people between ages 20-65 and 10 over 65 years old. Also, 80 people live in the Centers' Residential program in Tompkins County, which they provide through 13 group homes.

Adults Ages 20 to 65

The 2000 census identified 6,831 people in this age range as having disabilities. If about 5.1% need LTC, this would result in 348 people as needing LTC services.

The Finger Lakes Independence Center is a key organization; it works to empower all people with disabilities while creating an inclusive society through the elimination of social and architectural barriers. Their vision includes their being a voice for empowerment, agent for inclusion and catalyst for change.

The number of frail and dependent young adults has increased. Accidents, head injuries, early strokes and multiple sclerosis have left many adults disabled. Acquired Immune Deficiency Syndrome (AIDS), with cases having started in the 1980's, is expected to continue disabling younger adults.

Seniors ages 65 and over, particularly those 85+

Women comprise the majority of the elderly population. In 1990 they were 59% of those 60 and over and 75% of those 85 and over. The 2000 Census found that 61% of people 65 and over were women. This difference between the numbers of elderly females and males could balloon with the growth in the aging population.

Living alone often requires increased help with shopping, transportation, and personal care in addition to homemaking services. Elderly persons who are more functionally disabled use all services more frequently, including personal care and home health care.

The segment of the population most likely to require services for chronic health conditions are those 85 and older. This group, often called *the frail elderly,* account for approximately 1-2 percent of the total population. They also represent approximately 10 percent of the elderly population and typically account for more than 50% of all nursing home residents. Approximately 20% of people aged 85+ reside in nursing homes; a similar proportion use home health care.

The aging of the baby boomers is expected to have a dramatic effect on the need for services. This demand for services will require planning and a significant growth in resources. However, we do have time to prepare. The leading edge of the baby boomers, people born in 1946 will not reach age 85 until 2031.

The population tables below show the projected growth in the over 65 age group and, more significantly, the over 85 age group.

Tompkins County Population Trends

	All Ages	**0-59**	**60-64**	**65-74**	**75-84**	**85+**	**Total 65+**
1990	94,097	82,786	2,846	4,684	2,796	985	8,465
2000	96,501	84,534	2,710	4,637	3,368	1,252	9,257
2010 (Proj.)	100,371	86,005	4,460	5,095	3,273	1,538	9,906
2020 (Proj.)	100,821	83,247	4,768	7,572	3,609	1,625	12,806

The total population projections are from the Ithaca-Tompkins County Transportation Council moderate growth projections.

Percentage Differences

		Percentage Differences	
	2000	From 2000 – 2010	From 2000 - 2020
Ages 0 - 59	84,534	1.7%	-1.5%
Ages 60 - 64	2,710	64.6%	75.9%
Ages 65 – 74	4,637	9.9%	63.3%
Ages 75 - 84	3,368	-2.8%	7.2%
Ages 85+	1,252	22.8%	29.8%

Fortunately, the percentage of older adults who are disabled has been steadily DECREASING between 1982 and now.

Trends in Changes in Disability Rates

The National Long Term Care Surveys (NLTCS) collect information about chronic disability prevalence rates in the elderly United States population. As the chart below indicates, the level of disability has dramatically decreased since 1982. The percentage of people living in institutions has also decreased. This is due to changes in reimbursement policies and declining disability rates as well as the U.S. Supreme Court's 1999 Olmstead decision, affirming the rights of individuals with disabilities to live the in the most integrated, least restrictive settings.

Percentage of disability group estimates by age (NLTCS)							
Age and disability level	**1982**	**1984**	**1989**	**1994**	**1999**	**2004/ 2005**	**Relative changes**
Age 65–74							
Disabled	14.2	13.3	11.9	11.8	10.7	8.9	-37.3%
Institution	2	1.7	1.9	1.6	1.4	0.9	−54.6%
Age 75–84							
Disabled	30.7	29.8	29.4	26.2	23.4	21.9	-28.7%
Institution	8.1	7.1	7	6.3	4.3	4.1	−48.8%
Age 85+							
Disabled	62.1	65.9	61.4	58.5	55.6	49.7	-19.9%
Institution	27.2	26.6	26.1	24.6	19.5	15.6	−42.7%

PNAS November 28, 2006 vol. 103 no. 48 18374-18379 (Proceedings of the National Academy of Sciences)
National Chronic Disability Rates by Age http://www.pnas.org/content/103/48/18374.full

Although evidence points to recent health improvements at older ages, there is no guarantee that these trends will continue. Disability associated with the rising prevalence of diabetes and obesity in the younger population might offset the future decline in disability rates at older ages

As increasing numbers of older adults survive to 85+, disability in older adults associated with Alzheimer's and related dementia may also increase unless medical advances produce effective treatment and/or prevention of diseases of the brain that cause dementia.

Who provides LTC?

Long term health care is provided in four main, often overlapping, ways:

I. Informal assistance, primarily by family members. Informal care is estimated to provide more than 80% of all needed home care (National Family Caregiver's Assoc. 2000).
II. Supportive community services.
III. Home health care agencies.
IV. Residential facilities such as adult homes, assisted living facilities and nursing homes.

Long Term Care Continuum of Services

Different Home Venues

Home (single-family, apartments, other)
Independent Apartments (for seniors, people w/disabilities)
Independent Apartments (some services)

Supplements Self-Care provided in home

Unpaid Caregivers (family and friends)
Paid Caregivers, unaffiliated with an agency
Medical Adult Day Care (and Social Adult Day Care)
Consumer Directed Personal Care Aide
Licensed Home Care Agency (LHHA)
Certified Home Health Agency (CHHA)
Long Term Home Health Care Program (LTHHCP)
Traumatic Brain Injury Program (TBI)
Hospice and Palliative Care Services
Nursing Home Transition & Diversion Program

Key Community Services
Many supportive services, such as respite care, case management, food delivery, transportation assistance, and emergency response, also play an important and integral role in the long term care system.

Alternative Living Locations (Housing + personal/medical care)

Enriched Housing Program
Adult Home
Assisted Living (Medicaid, non-Medicaid, enhanced, and special needs)

Hospice residence
Skilled Nursing Facility (SNF), nursing home

Continuing Care Retirement Community (CCRC) – Kendal at Ithaca

Family and friends provide a significant portion of long term care.

In New York State:

1,923,778 caregivers

2+ billion hours of care per year

$20+ billion cost saving to our health care system

(Source: 2004 National Family Caregivers Association)

I. Family and Friend Caregivers

Much of long term care is done informally with people relying heavily on help from family and friends. Nationally over three-quarters (80%) of adults living in the community and in need of LTC depend on family and friends (i.e., informal caregivers) as their only source of help; 17% receive a combination of informal and formal care (i.e., paid help); only 6.5% used formal care or paid help only. (AARP) Even among the most severely disabled older persons living in the community, about two-thirds rely solely on family members and other informal help, often resulting in great strain for the family caregivers. (AARP)

Locally, COFA's surveys in both 1995 and 2004 found that, for people needing help with various activities of daily living, the "most common single helper was the spouse followed by combinations of other people."

Care provided by family and friends can determine whether older persons can remain at home. Nationally, 50% of the elderly who have LTC needs but no family available to care for them, are in nursing homes, while only 7% who have a family caregiver are in institutional settings. (Source: FCA: Women and Caregiving: Facts and Figures." *Family Caregiver Alliance).*

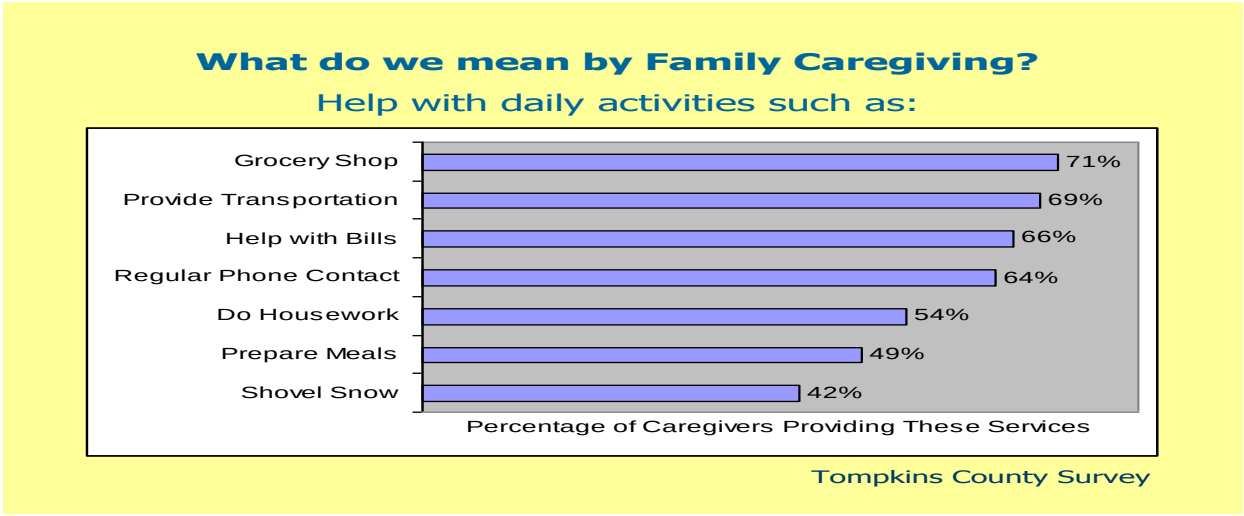
Family caregivers formerly isolated with their own individual problems are now receiving public recognition for the central role they play in the lives of the elderly. Programs originally designed exclusively for the aged themselves are now being redesigned to also assist, extend and relieve the ongoing care provided by the family.

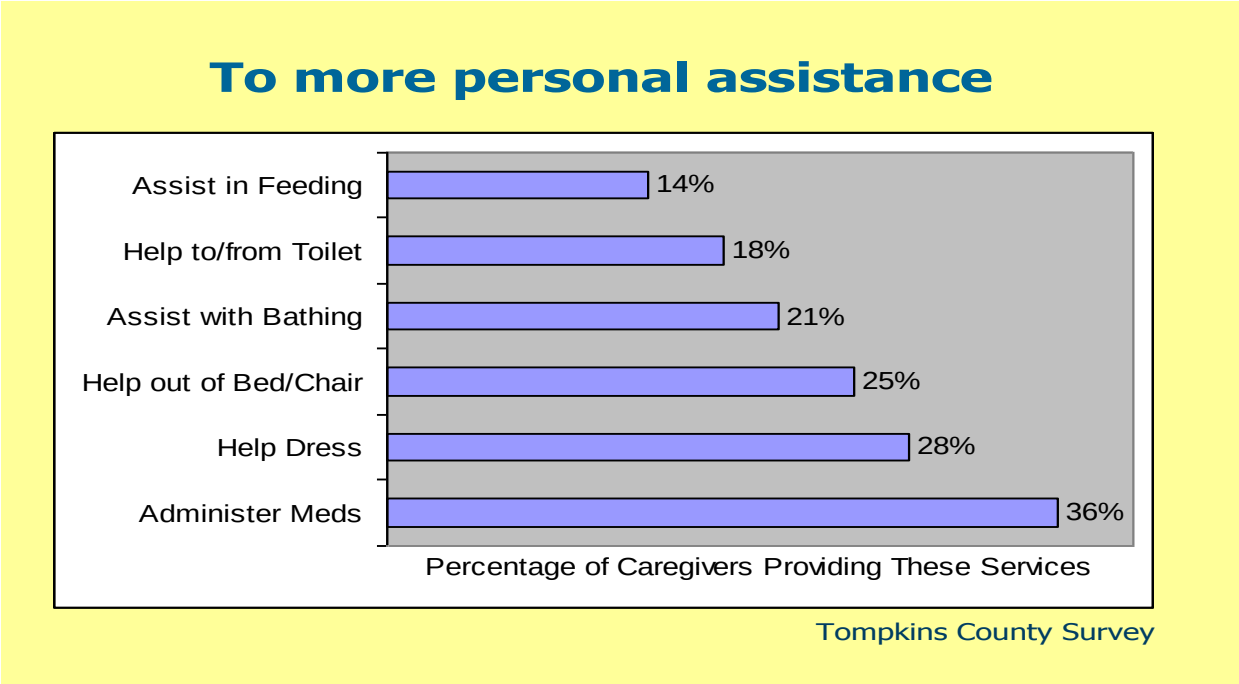
COFA maintains a Caregiver's Resource Center which provides information and support to individuals concerned about or caring for an aging or disabled relative or friend, near or far. The Center offers individual counseling, information and referral, caregiver training, a caregivers' newsletter and other publications. Books and videos are available for free loan. It also organizes support groups and provides workshops for caregivers, including Powerful Tools for Caregivers, a 6 week evidence-based training for family caregivers.

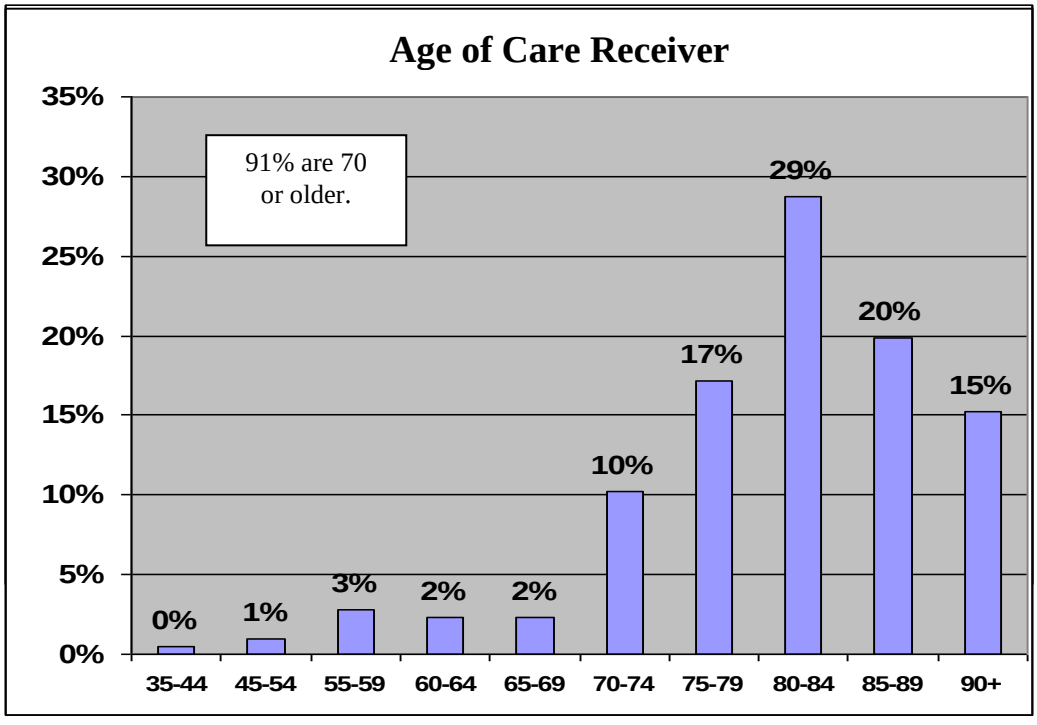
Family and Children's Service established a Caregiver Counselor Program to provide professional counseling in the home. It also provides grant-funded caregiver respite care service. Longview operates a social-model "Adult Day Community" which also can provide a needed break from caregiving to a family member. These programs provide much needed support, but they are now always threatened with budget cuts.

Tompkins Caregiver Survey

In 2003 the Long Term Care committee of the Health Planning Council surveyed people in the county who were informal caregivers. 225 people participated in the survey, yielding a rich glimpse of the local situation. Even this limited number provided 14,726 hours of unpaid care a month. At the rate of $10/hour, the value would be $1,767,120 per year. The charts below contain some of the data.

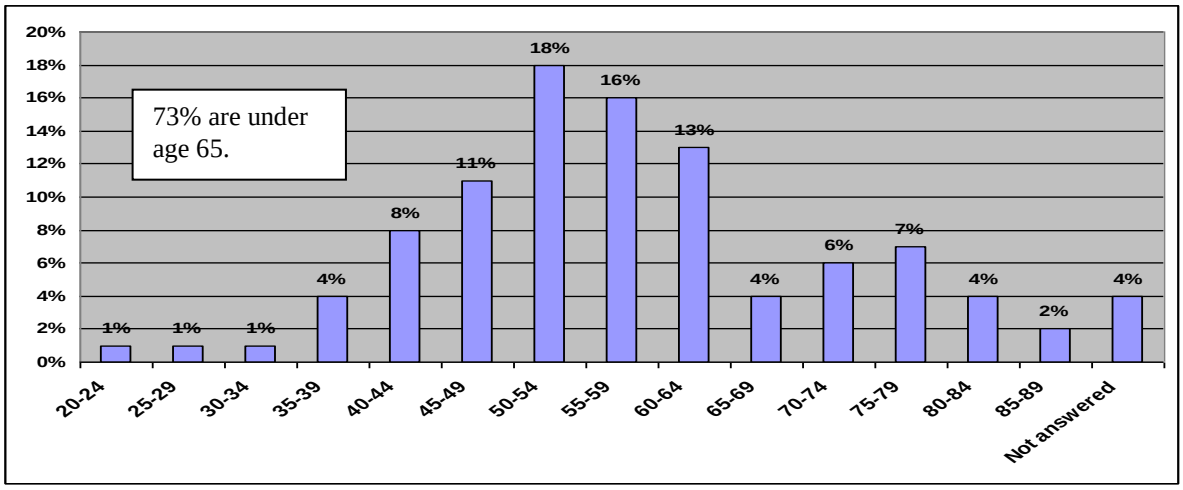




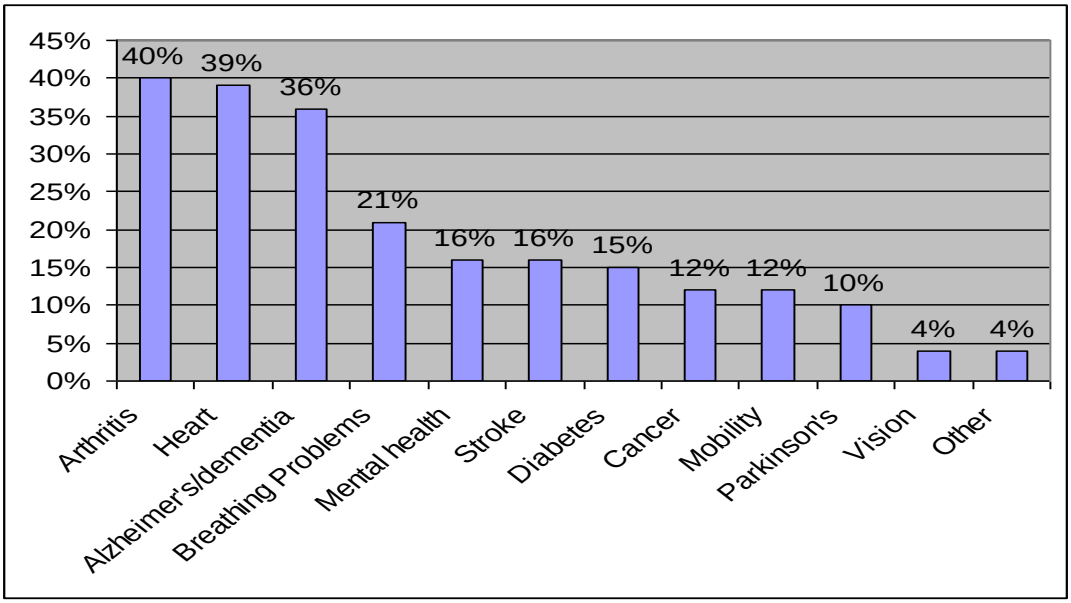


Survey results indicated that 61% of care receivers were parents; 19% were a spouse/partner, 10% were another relative and 10% were a friend/neighbor.

Age of Caregiver



Medical Conditions of Care Receiver



II. Supportive Community Services

Local services, such as the Tompkins Care Connection (LTC Services unit), Foodnet's Meals on Wheels, Gadabout and Hospice and Palliative Care Services can be used if a person resides in private homes or senior apartments. These programs are ***often critical*** in enabling people to maximize their independence and to age in place.

The trend towards community-based services as opposed to nursing home placement was formalized with the Olmstead Decision (July 1999) – a court case in which the Supreme Court upheld the right of individuals to receive care in the community as opposed to an institution whenever possible. {Family Caregiving Association}

Shorter hospital stays and increased usage of outpatient procedures – changes that have increased the effectiveness of medical care – have shifted responsibility toward unpaid providers of care from paid providers, increasing burdens on family caregivers. {Family Caregiving Association}

Some Changes in Services from 1996-2009

The following list of the many increases in community long term care services have made possible decreases in more-expensive hospital and nursing home care. This has resulted in a reduced need in number of SNF beds Many of these were identified as priority needs in the HPC 1996 Needs Assessment.

<u>Coordination + Assessment</u>
The Long Term Care Services unit was established in the early 1990's. It provides assessment & case management, information & referral, certifies eligibility for Medicaid home care programs and nursing home placement. Sponsored by the Tompkins County Department of Social Services and the Office for the Aging, this service is available at no cost to all Tompkins County residents regardless of age or income. In 2006, with NYS funding, this service was designated the NY Connects point of entry for long term care for Tompkins County residents and renamed Tompkins Care Connection. In 1996 they had about 500 phone calls. In the first three quarters of 2009 they had 742 requests for information, 368 from people over 60.

<u>Other coordination service changes</u>

- Case Manager at Titus Towers 1999
- Geriatric Care Management Service started by Family and Children's Service (F&CS) 2005
- Service Coordinator at McGraw House
- Service Coordinator at Ellis Hollow Apartments 2007 and Conifer Village Apartments 2008
- Partnership between Titus Towers and Redmoon Caregivers to provide on-site nursing/ case management 2009

<u>Family Support + Community Care</u>

- Adult day care - new social adult day care programs at Longview and Groton, and the opening and closing of medical adult day care at the Reconstruction Home {now Beechtree Center}1997
- Several new home health care agencies 1998
- Hospicare's Transitions program 1998
- Medicaid Consumer Directed Personal Assistance Program; coordinated by Finger Lakes Independence Center (FLIC) 1998
- Advocacy Center added a Crime Victims Assistance Program which includes elder abuse 1998
- Start of web sites from many agencies: Alterra (now Brookdale Senior Living), COFA, Elderhelp, FLIC, F&CS and Long Term Care Services 1999
- Longview adding another day in their adult day care program 1999
- Foodnet and Meals on Wheels consolidated Services 2000
- TCDSS received grant funding to work on education of the public regarding Elder Abuse. Funding obtained for 4 years 2000-2003

- COFA expanded Project Care to serve the rest of the county in addition to the Town of Dryden 2001
- Veteran's Administration Clinic opened in Cortlandville 2001 and one at Convenient Care in Lansing, Cayuga Medical Center 2003
- Hospicare expanded their palliative care services and changed their name to "Hospicare and Palliative Care Services" 2002
- Longview accepts Medicaid clients in their Social Adult Day Program 2002
- COFA, FLIC and OT department at IC received grant to fund "Try It Room" where consumers can borrow various kinds of assistive devices to try before purchasing them 2004
- Center for Life Skills, a rehabilitative program developed by Ithaca College to assist individuals who have experienced a stroke to meet their maximum potential 2004
- Changes in definitions and licensing requirements for assisted living programs 2005
- HPC secured funding to lead a coalition (Sharing Your Wishes) to encourage frail elders and others to do advanced health care planning 2005
- Annual Senior Care issue of Ithaca Child started through Family and Children's Service 2005
- Redmoon Caregiver's began as a new privately owned licensed home care agency 2005
- Community Dispute Resolution Center initiated "Wise Talk" program 2006
- For respite care - increased availability of community reinvestment funds 1998 and United Way funds at Family and Children's Service for in-home respite care. Discontinued respite service at Cayuga Medical Center, reduced number of SNF's offering in-facility respite care 2007
- More support for family caregivers – Powerful Tools for Caregiving Workshops offered by COFA 2008
- Comfort Keepers now offering training for home health aides and allowing other Tompkins County home health agencies to fill open training slots
- Cayuga Ridge Health and Residential Community (formerly Lakeside Nursing and Rehabilitation Center) now offering training for certified nurse aides to supplement individual agency training programs.

<u>Reducing the Need</u>

- Walking Clubs and Enhance Fitness classes for seniors, Lifelong
- Community task force on senior wellness sponsored by COFA and the Senior Citizens' Council
- Health Education Community Resources Directory by the Health Planning Council
- Cayuga Center for Healthy Living through Cayuga Medical Center 2008
- Parkinson's Exercise Class 2009
- Chronic Disease Self-management workshop offered through HPC and FLIC (Finger Lakes Independence Center) 2009

Hospice Care

Hospicare opened a 6-bed residential facility in 1995. They also offer a program of comprehensive care for terminally-ill patients and their families in their own homes; it also offers services in various nursing homes. They provide palliative physical care and emotional, psychological and spiritual support as well as help with chores, errands, transportation, legal counseling and bereavement counseling.

Faith Communities

Many local congregations provide services to their members and the community. These can include direct health care services, friendly visiting, shopping assistance among other types of help. Some also provide health education programs.

The chart below list many of these community services and the volume of services provided.

Key Supportive Community Services which may enable people to stay in their home.

In addition to the service volume noted here, there are unmet needs in many areas which may be limited by financial caps and worker availability.

		1993	1996 (98)	2001	2005	2006	2007	2008
Family and Friends		**An estimated 80% of care**						
Information and Referral								
COFA I&R (on FY April - March)			5,060	3,850	2,666	5,445	3,012	3,162
Lifelong (Senior Citizens' Council)			800		305	543		3000+
I&R and Assessment								
LTC Services/Tompkins Care Connection			500 calls					926 calls
Direct Care (in addition to home care agency data on a later chart								
Registry			209 requests	234	150	138	70	86
		(162 from people over 60)		(~185 60+)	(~119 60+)	(111 60+)		
EISEP (Expanded In-home Services for the Elderly Program)	Clients		102 (98)	158	171	180	182	214
	Hours		8,391 (98)	15,917	13,273	17,919	17,374	17,382
Respite - F&CS	Clients		49 (98)	32	30	56	52	
	Visits			1,023	943	965	826	830
	Hours			2,315	2,520	2,577	2,195	
	Waiting List			3	15	19	16	19
Respite - Longview	Clients			4	12	5	2	1
	Days of Care			177	502	54	67	31
Housing Support								
Housing Options for Seniors (COFA)			50	no longer				
Home Repair (Better Housing)			78					90
Home Repair (Ithaca Neighborhood Housing Ser)			74 households with 94 seniors				51	50
HEAP (COFA) – people 60+			447	667	646	693	960	922
Weatherization (COFA)			16	113	60	98	71	138

	1993	1996 (98)	2001	2005	2006	2007	2008
Food							
Foodnet (Congregate meals)	23,713	25,411	28,378	30,942	25,198	27,338	25,487
Foodnet (Home-Delivered meals)	58,218	68,673	115,978	167,412	178,737	171,036	156,923
Meals on Wheels (CMC and ACT)	10,789	8,191	Merged with Foodnet in Dec. 2000				
Food Shopping Program (Southside)			389 hours	333	321	273	234
Transportation Medicaid will pay for transportation to medical care for Medicaid clients							
FISH (Friends In Service Help)	338 trips	568 trips				1,702 one-ways	
Gadabout one-way trips (about 40% medical) (including Paratransit Services)		37,377	56,000	62,243	58,275		63,809
Durable Medical Equipment							
Loan closets - FLIC	153	341 (225)	335	579	564	675	854
Loan closets at American Legions in Dryden, Groton, Trumansburg							
Medical equipment is also available at Franciscan Health, Guthrie, Lincare, Olsten Kimberly Quality Care, Professional Home care and some pharmacies.							
Other							
Friendly Visitor Program (COFA)		93 people	113	78	68	52	64
Project Care (COFA)				504 visits	406 hours	500 hours	313 visits
Adult Day Community Program Clients			12	19	16	8	14
Longview Days of Care			341	822	590	165	476
Legal Assistance (COFA)		44 people	39	48	60	46	38
PERS-Personal Emergency Response System COFA)		169 people	407	500	537	622	663
HIICAP, both COFA and Lifelong	(Health Insurance Information and Counseling and Assistance Program)						
Clients served		202			703	614	459
F&CS Caregiver Counseling		83 (98)	85	145	95	79	80
Clients							
Visits			82	616	636		821
Wise Talk (Community Dispute Resolution Center)						175 people	
Many other groups in our community also help people remain in their home. These include the faith community, Mental Health Assessment - geriatric unit (TCMHD), Financial Management Services, Case Management Services (with private consultants), Mail home library outreach (free).							

III. Home Health Care

Paid home health care supplements informal care, community-based services and when there are no family/friends able to provide the needed help. Substantial demand for home-based services exists in Tompkins County. An estimated 75% of the care provided is given to seniors. At this time there are often waiting lists for home care services. In addition, respite care and the EISEP program (Expanded In-home Services for the Elderly Program) often have waiting lists because there is not enough money in their budgets to meet all the need or there is a shortage of direct care personnel.

Two types of agencies provide services in the County: (See Appendix A and B for details.)

2 Certified Home Health Agencies (CHHA's) that provide skilled nursing care as well as physical therapy, speech therapy, occupational therapy and other services as well.

5 -8 Licensed Home Health Agencies (LHHA's) that offer nursing, home health aide, personal care aide and a variety of other services as well. Additional LHHA's are licensed by the State to include Tompkins County in their service area but are not yet providing much care here.

People also make private arrangements with individuals to provide care. The Registry, a program of the Women's Opportunity Center, operates a free listing and referral service for caregivers who provide in-home help to people who are ill, disabled or in need of household services or companions. They list health aides, housekeepers, companions, cooks, drivers and nurses.

Types of professionals providing most of the care
Registered Nurse (RN) licensed by NYS to do specific medical care.
Licensed Practical Nurse (LPN) licensed by NYS to do a lower level of medical care.
Home Health Aide (HHA) provides semi-skilled services and personal care such as bathing and dressing
Personal Care Aide (PCA) Level I provides primarily housekeeping duties and does not include hands-on care. Level II is primarily assistance with hands-on care. (A DSS classification)
Homemaker assists with home management activities such as meal preparation, shopping, etc.

Expanded In-Home Services for the Elderly EISEP
Provides non-medical, in-home services and case management to functionally impaired elderly. Can include help with bathing, dressing, cooking, shopping, laundry, and housekeeping. It is designed for low income clients not eligible for Medicaid. Cost sharing on a sliding scale is mandatory. EISEP contracts with various licensed agencies to provide PCA level care. (NYS Office for the Aging and Tompkins County funding, administered by Tompkins COFA)

Long Term Home Health Care Program LTHHCP
Home care services to recipients who are medically eligible for care in an institutionalized setting. Services include nursing, medical, social services, home health aides, personal care aides, nutrition, medical supplies and equipment and other therapeutic and related services. Cost may not exceed 100% of monthly cost of nursing home. Fourteen people are now in the program in Tompkins County. Recipients can qualify for Medicaid using more lenient nursing home financial criteria than used by participants in other home care programs. There are 41 spaces in this program. (Medicaid funding; used to be called "nursing home without walls".)

Consumer-Directed Personal Care Aide Program
This NYS program empowers Medicaid recipients to hire their own PCA's rather than having to receive care through an agency. This allows the client/patient to have more control over who comes into their home, and more flexibility in scheduling. The disadvantages are that there is no back-up system, no minimum qualifications or training, and that the consumer needs to be trained in how to supervise an employee and to keep the necessary records. (Medicaid funding; administered by Finger Lakes Independence Center)

Home Health Care Visits		Units of Service											
		1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Visiting Nurse Service	Nursing	8,836	8,639	7,964	6,579	5,620	4,993	5,318	N/A	N/A	3,575	3,670	3,189
	HHA hrs.	18,146	11,936	12,734	8,706	7,696	4,390	3,490	N/A	N/A	1,215	776	425
	PT	3,177	2,936	3,004	2,410	2,269	2,910	2,700	N/A	N/A	2,914	3,560	2,120
	ST	297	247	132	139	116	85	121	N/A	N/A	61	48	64
	OT	274	342	291	268	526	458	372	N/A	N/A	183	289	45
Tompkins County Health Department	Nursing	8,489	7,861	7,128	6,610	6,435	5,133	4,698	5,644	5326	5,151	5,514	5,378
	HHA hrs.	35,480	29,012	19,685	16,885	14,776	12,732	11,123	12,102	9837	9,107	10,134	8,983
	HHA visits	23,302	18,540	12,171	9,874	8,721	7,301	6,560	7,025	5650	5,706	5,788	5,645
	PT	1,519	1,699	1,059	992	832	963	1,027	1,230	1815	1,547	2,109	2,192
	ST	179	155	89	55	119	94	45	164	192	161	120	171
	OT	76	134	127	176	156	167	161	96	130	75	245	307
Unduplicated Patient Count					573	500	460	472	540	571	521	600	615

From TCHD: Note that 2005 shows a decrease in nursing visits, however, this does not reflect a reduction in service: rather, an unduplicated patient count shows that 571 clients were served in 2005 vs. 540 in 2004. Physical Therapy continued the 2004 trend with increases in visits and # of clients served.

Medicare Visits, Tompkins County Health Department												
	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Skilled Nursing	6,069	5,478	4,864	4,781	4,436	3,928	3,446	4,345	3,805	3,503	3,632	3,587
Physical Therapy	1,537	1,298	864	858	613	814	841	965	1,445	1,273	1,381	1,568
Occupational Therapy	37	84	94	129	124	138	130	58	96	67	195	201
Speech Therapy	155	131	79	47	107	70	45	52	156	106	55	140
Home Health Aides	18,469	14,736	8,760	6,592	6,564	5,671	5,403	5,136	3,908	3,679	2,992	3,040

Home Health Care's major revenue source, Medicare, reimburses services through the Prospective Payment System based on a complex formula for every 60-day episode of care. In 2006, 'episode' statistics were added and provide a more accurate view of program activity and growth.

From Long Term Care Services, TCDSS	**1998**	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**
EISEP *(Expanded In-Home Services for the Elderly Program)*											
- Recipients	102	172	235	158	202	180	188	171	180	182	214
- Hours	8,391	16,309	16,237	15,917	16,243	16,208	15,349	13,273	17,919	17,374	17,382
Medicaid PCA *(Personal Care Aides)*											
- Recipients	130	329	332	150	246	254	271	313	346	349	
- Hours	28,600	73,886	99,524	119,133	140,450	185,360	233,015	Est. 272,000	300,164	303,280	

Consumer Directed Personal Assistance Program (CDPAP)

Administered by Finger Lakes Independence Center
Funded through Medicaid - *Started 2/98
These are a subset of the Medicaid PCA services above.

	Clients	**Hours of service**
1998*	14	3,947
1999	25	9,985
2000	35	18,892
2001	43	24,624
2002	58	32,226
2003	74	67,010
2004	90	89,952
2005	114	115,068
2006	137	159,921
2007	138	177,681
2008	125	178,341

With CDPAP:

Recipients have flexibility and freedom in choosing their caregivers.

Recipients must be able and willing to make informed choices regarding the management of the services they receive, or have a legal guardian or designated relative or other adult able and willing to help make informed choices.

The consumer or designee must also be responsible for recruiting, hiring, training, supervising and terminating caregivers, and must arrange for back-up coverage when necessary, arrange and coordinate other services; and keep payroll records.

Respite and Caregiver Counseling - Family & Children's Services													
		1997	**1998**	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**
In-Home Respite	Clients	48	49	48	27	32	49	29	28	30	56	52	
	Visits				528	1,023	1,182	1,254	1,228	943	965	826	830
	Hours				1,106	2,315	3,209	3,147	3,001	2,520	2,577	2,195	
	Waiting List				7	3	10	12	24	15	19	16	19
Caregiver Counseling	Clients	73	83	70	57	85	98	111	118	145	95	79	80
	Visits				363	82	286	553	550	616			821
Total $ for both programs		$69,479	$69,467	$102,341	$97,600	$102,437	$126,183	$127,567	$133,654	$133,654	$133,654	$133,654	$133,654

**In 2001, 3.5 months with no caregiver counselor*

Longview Services		**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**
Adult Home	Clients with SSI	26	19	14	17	19	18	23	
Adult Day Community Program	Clients	12	12	9	13	19	16	8	
	Days of Care	341		499	577	822	590	165	
	$ Spent	26,162	18,347	12,645	21,120	29,221	19,653	6,473	
Respite Program	Clients	4	4	14	14	12	5	2	
	Days of Care	177	145	637	688	502	54	67	
	$ Spent	11,440	10,984	46,934	41,276	32,791	7,215	3, 741	

***** Budget doesn't include any increase for SSI. Lack of substantial increase continues to impact revenues in the Adult Care Facility, in which individuals are admitted regardless of income.

IV. Residential Care

These include 16 senior apartments, 6 adult home care facilities, 1 lifecare community and 4 skilled nursing facilities (SNF's, also called nursing homes or residential health care facilities, or RHCF's). (See Appendix C for definitions of residential facilities.) The supply of residential facilities has increased over the years.

	1977	**1984**	**1994**	**1996**	**2009**	**Planned Changes** (details below)
Source of data	COFA	COFA	COFA	HPC	HPC	
Senior Citizen Apartments	418	718	823	972	1,194	+ 32
Domiciliaries	179	158	-	-		
Adult/Family Type Homes / Assisted Living	-	-	88	109	181	+ 90 (+90 proposed)
Health Related Facilities	100	140	-	-		
Skilled Nursing Facilities	292	332	520	555	555	- 160
Total	**989**	**1,348**	**1,431**	**1,636**	**1,930**	

Between 1996 and 2009, residential capacity has increased by 294 units or beds with most of these being from adult home/assisted living beds. Of these:

- Senior apartments increased by 222 units; 101 at Longview, 72 at Conifer Village, 46 at Brookdale Senior Living (Alterra) and 4 at Ellis Hollow (Kendal decreased by 1 unit).
- Adult homes increased by 72 beds; 36 at Brookdale Senior Living (Alterra), 24 at Kendal, 18 at Bridges, and other small changes. (Longview decreased by 17 beds).
- Nursing home beds remained stable at 555. This is scheduled to change in 2010 when Cayuga Ridge Health and Residential Community (previously Lakeside Nursing and Rehabilitation Center) will decrease by 160 beds; they will also be adding the 90 assisted living beds and a 25-slot Adult Day Health Care Program.

<u>Residential Services – Summary of changes since 1997</u>

- Ombudsman program now in nursing homes and with the hospice program 1998
- Opening of Alterra (Sterling House, Clare Bridge Cottage), 36 adult home beds with an Alzheimer's program and 46 senior residences 1999 [Name changed to Brookdale Senior Living in 2008]
- Addition of 24 adult home beds, Kendal at Ithaca 1999
- Elizabeth Classen opened Bridges Cornell Heights, a 10-bed senior care facility 2002
- Berger Commission report released requiring the closing of Lakeside Nursing Home 2006
  Numerous interventions sponsored by COFA, HPC and others to negate Berger Commission requirements. Requirements amended 2007
- Additional independent apartments available at Ellis Hollow and Conifer Village 2008
- Lakeside received approval to convert to 100 SNF beds, 55 Assisted Living Program (Medicaid eligible) beds, 35 adult home beds, 25 adult Day Health Program slots 2009 Many of the existing SNF residents can be safely transitioned to these less restrictive levels of care.
- RSVP organized "Wonderful Wheelchairs" program located at Lakeside. This program was started to repair and allocate wheelchairs to residents of all of the SNFs 2009
- Vitale proposed to build The Village at South Pointe as a 60 bed adult home and a 30 bed Medicaid ALP (15 of which will be memory care) 2009

Capacity of Facilities – 1996 through 2009

# of units	1996	2003	2009	Planned/ *Proposed*
Senior Citizen Apartments				
Brookdale Senior Living (was Alterra Sterling House of Ithaca)		46	46	
Center Village Ct, Groton	60	60	60	
Conifer Village			72	
Ellis Hollow Rd, Ithaca	100	100	104	
Fountain Manor, Sl'ville Spgs	24	24	24	
Juniper Manor I, T'burg	40	40	40	
Juniper Manor II, T'burg	20	20	20	
Kendal at Ithaca	215	214	214	
Lehigh Crossing, Freeville	24	24	24	
Longview (Ithacare)		101	101	+ 32 Enhanced Assisted Living
McGraw House, Ithaca	105	105	105	*+ 25 to 45 independent apts*
Newfield Garden, Newfield	28	28	28	
Oak Hill Manor Cottage	3	3	3	
Schoolhouse Gardens, Groton	28	28	28	
Titus Towers I & II, Ithaca	235	235	235	
Willowbrook Manor, Dryden	50	50	50	
Woodsedge, Lansing	40	40	40	
Total	**972**	**1,118**	**1,194**	
Adult/Family Type Homes / Assisted Living				
Andrus, Paula, Dryden	3	0	0	
Bridges Cornell Heights, Ithaca		10	28	Now Assisted Living
Brookdale Senior Living (wasAlterra Clare Bridge of Ithaca)		36	36	Now Assisted Living
Cayuga Ridge Health and Residential Community (was Lakeside Nursing Home)		+55 Medicaid ALP; +35 adult home beds		
Deer Haven, Spencer		2	5	
Evergreen House, Jacksonville	4	4	6	
Farkas, Joanna, Slaterville	3	4	0	
Kendal at Ithaca	12	36	36	
Ithaca Heritage House, Enfield	2		0	
Ithacare/Longview	81	60	64	
Old Hundred Home, Ithaca			6	
The Village at South Pointe (Vitale)		*+30 Medicaid ALP; +60 adult home beds*		
Timely Manor, Ithaca	4	4	0	
Total	**109**	**156**	**181**	

# of units	1996	2003	2009	Planned/ *Proposed*
Developmental/Psychiatric (no updated data available for developmentally disabled or psychiatric beds)				
Broome Developmental, Ithaca	50	50	61	
HOMES, Ithaca	112	112		
Lakeview Mental Health Services			38	
Unity House			54	
Franziska Racker Centers, Tompkins (13 group homes)	30	80	80	
Total	**192**	**192**	**192**	**192**
Skilled Nursing Facilities				
Beechtree Care Center (was Reconstruction Home)	120	120	120	
Cayuga Ridge Health and Residential Community (was Lakeside Nursing Home)	260	260	260	- 160
Groton Nursing Facility	80	80	80	
Kendal at Ithaca	35	35	35	
Oak Hill Manor	60	60	60	
Total	**555**	**555**	**555**	**395**
Hospice Residence				
Hospicare	**6**	**6**	**6**	**6**

Sources: Directory of Licensed Assisted Living Residences in Tompkins
http://www.nyhealth.gov/facilities/assisted_living/licensed_programs_residences.htm

Service Area

Residential facilities now serve primarily Tompkins County residents. In 1996, 98% of people in the senior apartments had previously been either Tompkins County residents (75%) or have family/friends in Tompkins County (23%). In 1996, nursing homes had 71% of people from the county; this was up dramatically from the 1984 survey which found only 44% of patients being in-county residents. We did not obtain this data for 2008.

The catchment area for placement in Tompkins County's nursing homes is greater than the boundaries of Tompkins County. Rural Schuyler, Seneca, and Cortland Counties in particular look to Tompkins for primary care and nursing home needs. We also recognize that some Tompkins residents receive care out of the county.

Waiting Lists

Estimating an unduplicated count of the number of people on waiting lists is difficult because many people are on multiple lists and do not always notify the facility when they make other arrangements.

For skilled nursing facilities availability has dramatically improved; all nursing homes reported no waiting lists. The Berger Commission found that Tompkins County was over-supplied with skilled nursing facility beds and under-supplied with lesser care levels of beds. "Although occupancy rates have been declining, New York's nursing homes have increased the numbers of people they serve. Shorter-term stays for sub-acute care have become so prevalent that the number of total nursing home admissions has more than doubled since 1997. The

rapid growth of sub-acute services, together with rapid resident turnover rates (less than 30 days length-of-stay), reduces the occupancy of an efficient provider. The State's nursing home average length of stay decreased from approximately one year in 1997 to 217 days in 2003. Patient turnover leads to vacant beds due to admission/discharge timing issues, the need to match roommate gender as well as other factors."

There is a documented excess supply of nursing home beds in the DOH bed need methodology, and the county's nursing facilities as a whole operate at only 92.7% occupancy. Tompkins County has only 28 non-institutional slots per 1,000 seniors (compared to a statewide average of 33) and has NO ALP (Assisted Living Program) beds or adult day health care slots at all within its borders."

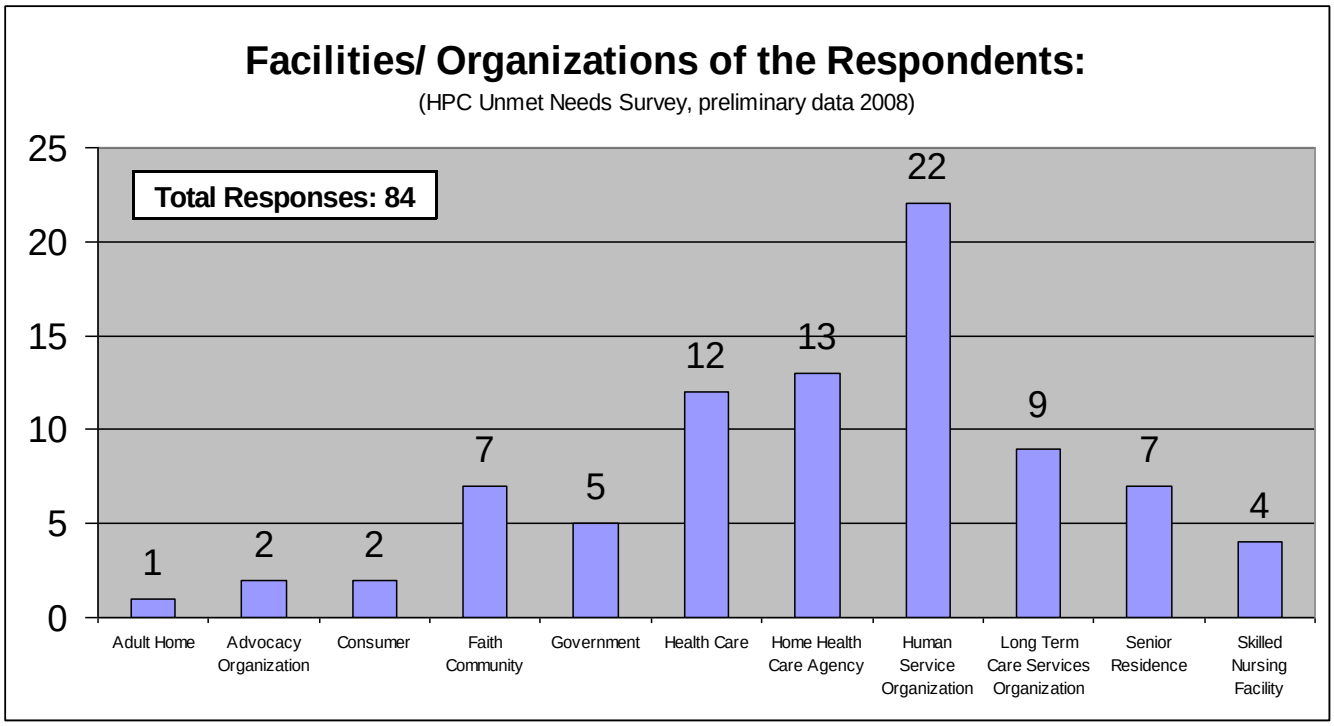
Unmet LTC Needs survey

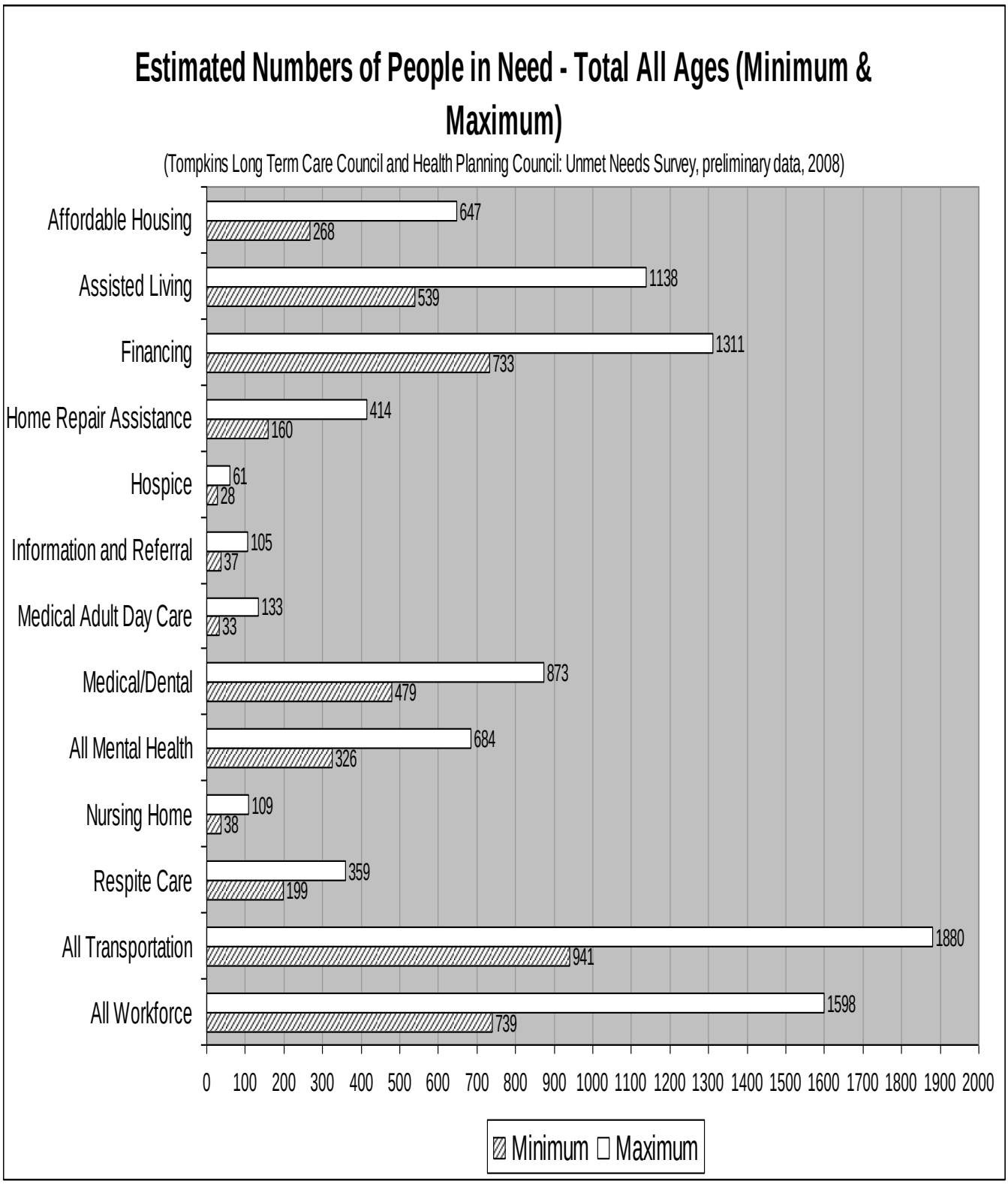
The Long Term Care Committee conducted an assessment of the long term health care needs of people in our community in the summer of 2008. We requested their input about the UNMET NEEDS for children, adults, and older adults who have illness and disabilities requiring long term health care.

We surveyed all senior residences, adult homes, residential health care facilities, home care agencies, community referral agencies, faith community leaders and representatives of senior groups. These organizations interact with countless patients/clients every year and were in a good position to know about what services they are NOT able to find for their clients.

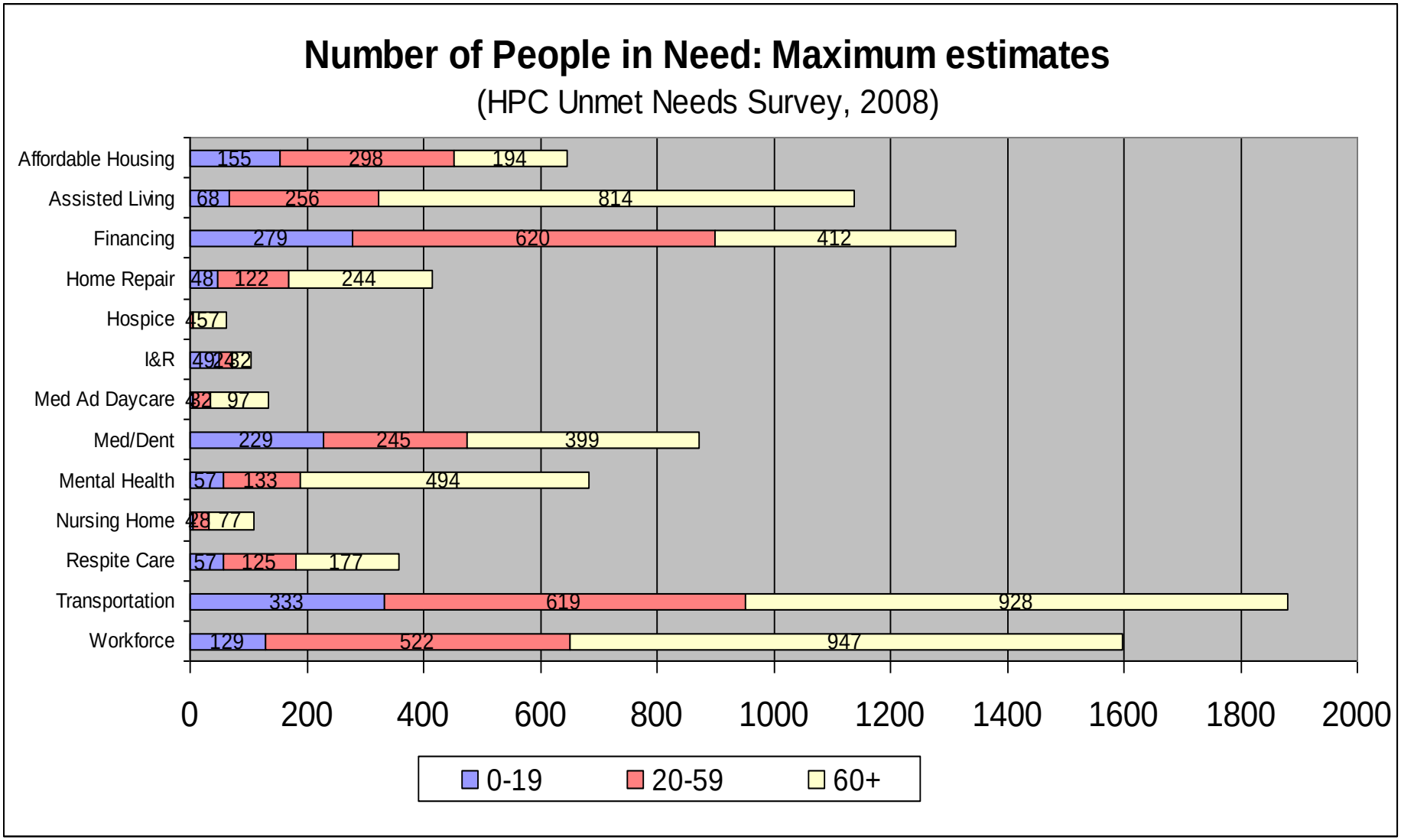
In addition to identifying unmet needs, we asked "About how many people a year do you see that have this unmet need?" We further asked for these estimated numbers of the need by broad age categories.

The charts below detail some of the key results. Additional information is in Appendix E.




Estimated Numbers of People in Need - Total All Ages (Minimum & Maximum)
(Tompkins Long Term Care Council and Health Planning Council: Unmet Needs Survey, preliminary data, 2008)
Affordable Housing
647
268
Assisted Living
1138
539
Financing
1311
733
Home Repair Assistance
414
160
Hospice
61
28
Information and Referral
105
37
Medical Adult Day Care
133
33
Medical/Dental
873
479
All Mental Health
684
326
Nursing Home
109
38
Respite Care
359
199
All Transportation
1880
941
All Workforce
1598
739
0 100 200 300 400 500 600 700 800 900 1000 1100 1200 1300 1400 1500 1600 1700 1800 1900 2000
Minimum
Maximum

.


Number of People in Need: Maximum estimates
(HPC Unmet Needs Survey, 2008)
Affordable Housing
155
298
194
Assisted Living
68
256
814
Financing
279
620
412
Home Repair
48
122
244
Hospice
4
57
I&R
49
24
82
Med Ad Daycare
4
32
97
Med/Dent
229
245
399
Mental Health
57
133
494
Nursing Home
4
28
77
Respite Care
57
125
177
Transportation
333
619
928
Workforce
129
522
947
0
200
400
600
800
1000
1200
1400
1600
1800
2000
0-19
20-59
60+

This next section of the needs assessment contains:

Related Issues

- Importance of local assessment and coordination
- Shortage of health care professionals, particularly direct health care workers
- Insufficient mental health services
- Focus on the most integrated setting (MISCC)
- Need for accessible housing
- Transportation difficulties

Promising Trends

- Falls prevention
- Transitions of care
- Transforming nursing home care (Green House, Small House, Eden Alternative)
- Community cooperatives
- Powerful Tools for Caregivers
- Chronic Disease SELF-management
- Advance health care planning (Sharing Your Wishes, MOLST, etc.)
- Hospice and palliative care services

Importance of Local Assessment and Coordination

Periodically New York State legislators propose a plan to develop regionalized assessment centers for LTC, removing this function from local social service districts.

There are many reasons why this would disadvantage Tompkins County consumers of Long Term Care. These include:

- Rural counties are typically on the outskirts of the Regional Centers and as a result, services suffer

- DOH has developed Regional Resource Development Centers (RRDS) for both TBI (Traumatic Brain Injury) and NHTD (Nursing Home Transition and Diversion) Medicaid Waivers, it seems like a logical place for these assessments centers to also develop – Tompkins County's RRDS is in Broome County

- It took many years before the RRDS could provide TBI services in Tompkins County because they hadn't developed a provider network, it's taken 1 year to enroll our first client in the NHTD waiver program for the same reason

- Our local LTC system is well developed and coordinated – these connections would be lost with a regional center

- A lot of time, money and effort has been invested in NY Connects – how does that fit in to all of this?

- DOH has provided **no training or direction** for local districts on how they would like assessments completed by local district staff, regulations have not been updated in many years and are a mess. Handing this morass over to assessment centers will not accomplish the goals for consistency they have set forth

- What would such a center cost? Currently TCDSS provides information and referral, case management, authorization, and in-home assessment services to approximately 300 Medicaid clients per year with a staff of 4 RN's

- DOH has been slow to address key issues that impair consistency in providing in-home services: lack of appropriate housing options for seniors and shortage of community based home care aides

- Local districts will always be responsible for those consumers that a regional assessment center might deem "non-compliant", what incentives would the regional centers have to serve difficult clients

(Source: Liz Norton, RN, Director, Adult and Long Term Care Services, Tompkins County)

The CASA (Community Alternative Systems Agency) **Association of New York State** developed a White Paper "**Restructuring Medicaid Home Care in New York State:** ***A CALL TO ACTION Winter 2009***

Recommendations from the White Paper are in Appendix F.
The full report is available on http://broomecounty.net/broome/files/casa/pdfs/ACallToAction.pdf

Shortage of Health Care Professionals, particularly direct health care workers

Direct health care workers (Home Health Aides, Certified Nursing Assistants, Personal Care Aides) provide the bulk of the hands-on care that people require. Providers are experiencing difficulty recruiting nurses, home health, personal care and nurse aides to keep up with demand for their services. Low pay and benefits make this hard. For example, home health aides are paid $9-$11/hour, have few benefits and usually cannot be guaranteed a 40-hour work week. Also it is difficult to find aides if someone needs care more than 6 hours a day.

Training is often offered free from some local agencies, however it could cost around $700 and people often cannot afford to stop working their current job for the two weeks it takes for the training.

Changes in Responsibilities of Personnel
There is a trend of shifting responsibilities to a lesser trained person whenever possible. For example, nurses do what the MD's used to do; HHA's what the nurses did. There is also a move toward greater distinction between Home Health Aide services and Personal Care services. Home Health Aide services are becoming more technical and result in increased cost. Home Health Aide capabilities have expanded with greater scope for their practice; however there have also been reductions in required training.

The 2008 HPC Long Term Care Unmet Needs Survey documented the extensive need for additional health care workers.

Age	Number Unmet Cases
0-19	117
20-59	275
Age 65+	801
Total	**1,193**

In 2009, the County Office for the Aging secured a grant from the Community Health Foundation of Western and Central New York to "Improve Paraprofessional Training and Retention in Tompkins County." The purpose of this project is to increase the ranks of the long term care workforce, and to equip organizations and facilities with tools to improve the retention rates of direct care staff. The goal of the project is to address long term care workforce issues in Tompkins County through a two-pronged planning initiative including: 1) development of a plan to improve and streamline the training/certification of direct care workers and 2) development of a plan to incorporate best practices for retention of direct care workers among healthcare organizations.

The original meeting on March 13, 2009 included over 50 providers who were introduced to the grant and asked for their advice and feedback. As a result 2 smaller work groups were created; a Training group and a Retention group.

After considering several options for training, the one that was selected, as it was the most efficient and cost-effective, was utilizing Comfort Keepers, a local agency, for the community home health aide (HHA) trainings. One training has been held and 3 more are scheduled in the first half of 2010. Certified Nursing Assistant (CNA) trainings are also scheduled at Cayuga Ridge Health and Residential Community utilizing a T-S-T BOCES trainer. One session has been completed and 3 more are scheduled for the first half of 2010. These should add a total of 32 CNAs and 40 HHAs to the workforce. Tompkins Cortland Community College Biz has assisted in obtaining funding to subsidize these trainings in Tompkins County.

In August 2009 the Retention working group met with Dr. Rhoda Meador from CITRA (Cornell Institute for Translational Research on Aging) and have joined the pilot testing of CITRA's Retention Specialist program training tailored for the home care industry. It is expected that by the end of June 2010 Retention Specialist Training will have been offered to all local home care agencies. The skilled nursing facility curriculum will also be offered to area facilities.

This has been a VERY successful initiative. A progress report is in Appendix G.

Insufficient mental health services

In Tompkins County, key organizations addressing mental health issues are the Mental Health Services Board (including the Office of Mental Retardation and Developmental Disabilities) and the Mental Health Association.

In 2002, the percentage of older persons with moderate or severe memory impairment ranged from about 5% among persons aged 65-69 to about 32% among persons aged 85 or older. {Federal Interagency Forum on Aging-Related Statistics, 2004}

More mentally ill people ages 22 to 64 are moving into nursing homes across the United States, according to a new report from DB Techno which uses data from the Centers for Medicare and Medicaid Services. Overall, the number of people ages 22-64 living in nursing homes has increased by 41% from 2002 to 2008. **http://www.dbtechno.com/health/2009/03/22/more-mentally-ill-people-moving-into-nursing-homes/**

The Older Adult Committee, a focus group of the Mental Health Subcommittee of the Tompkins County Community Mental Health Services Board is dedicated to identifying and resolving gaps in services to older adults with mental illness in Tompkins County. In November 2007 they sent a letter to the Commissioner of Mental Health outlining concerns about mental health services to older adults, particularly those with the dual diagnoses of dementia and mental illness. Key points are below; the full letter is in Appendix H.

Service providers in Ithaca and in the upstate area frequently experience difficulties in obtaining inpatient and inpatient psychiatric support for geriatric dementia. These problems include the following:

- Psychiatric facilities are ill-equipped to provide care to geriatric patients requiring nursing and activities of daily living assistance, and are denied adequate reimbursement when they do provide care for this population.
- Geriatric residential facilities are often unable to access outpatient psychiatric support to provide care for residents with severe behavioral issues, and are forbidden by regulation to retain residents who become a danger to themselves or others.
- Mental health providers often lack experience with geriatric issues, and are ill-equipped to treat individuals with dementia.
- Long Term Care providers are not equipped to handle residents with severe psychosis or behavioral issues.
- Older adult patients and their families face a system that is unable to provide the support and care that they need.

- Medicare regulations do not cover therapy for residents with dementia due to an assumption that the demented resident cannot benefit from counseling or other therapeutic programs, an assumption that is unwarranted in many cases.

New York State: Listening Tour Talking Points Regarding Geriatric Mental Health

- 20% of older adults have a diagnosable mental disorder such as dementia, depression, anxiety, or schizophrenia
- Virtually all of them also have chronic health conditions
- Adequate service for older adults requires the integration of health, behavioral health, and aging services
- Integrated services are essential for:
    - Aging people with long-term psychiatric disabilities, who are at high risk for obesity, hypertension, diabetes, heart disease, and pulmonary conditions and whose life expectancy is about 25 years less than the general population
    - People with chronic health conditions such as diabetes who are also depressed because co-occuring disorders complicate and increase the cost of health care
    - People at risk of placement in, or already in, nursing homes. Over 50% of people in nursing homes have mental and/or behavioral problems that contribute to their placement. Many also have had family caregivers who "burned out"
    - People with less severe mental and substance abuse disorders who go to primary care physicians who generally are not skilled in the identification or treatment of mental illness or substance abuse.
    - People who do not seek help from either health or mental health professionals but do use services provided through the aging system.
- Therefore:
    - Long-term care reform efforts should include a focus on mental health of people at risk of placement and their family caregivers.

Geriatric Mental Health Alliance, Services Integration

Most Integrated Setting Coordinating Council (MISCC)

The NYS Most Integrated Setting Coordinating Council (MISCC) was established in 2002 for the purpose of developing a comprehensive Statewide plan to ensure that people of all ages with physical and mental disabilities receive care and services in the most integrated settings appropriate to their individual needs. This is an effort for NYS state agencies to coordinate programs/services/regulations to achieve the larger goal of enabling individuals with disabilities to receive care in the most integrated, least restricted settings. Participating State agencies include the Office of Mental Health, Department of Health, State Office for the Aging, Office of Mental Retardation and Developmental Disabilities, Education Department, Office of Alcoholism and Substance Abuse Services, Division of Housing and Community Renewal, Department of Transportation, Office of Children and Family Services, and the Commission on Quality of Care and Advocacy for Persons with Disabilities.

The 2010-2011 draft MISCC plan outlines several goals and implementation actions related to Housing, Employment, Transportation, Long Term Care and Community Based Treatment. The LTC section is in Appendix I. The full report is on: http://www.omr.state.ny.us/MISCC/

Accessible Housing

Universal design: creating a home for everyone, regardless of age or ability. It includes home design features and products that make a home safer and more comfortable for all residents, even when their needs and abilities change. The Center for Universal Design at North Carolina State University, among others, provides information and resources: www.design.ncsu.edu:8120/cud.

Home Modification: Adding a ramp, changing the door handles, installing a grab bar in the bath are just some examples of home modifications that can help someone increase the safety of living in their current home.

Transportation

Transportation was the top unmet need identified in the 2008 survey. People particularly felt an unmet need for transportation for medical appointments, including ones outside the county.

This is a VERY difficult problem to address.

In 2008, Gadabout provided 63,809 one-way trips. An estimated 40% of these are for medical reasons. Other current resources include ADA Paratransit, FISH (Friends In Service Help, volunteers providing trip to medical appointments), taxis, TCAT bus service, and some faith communities. For eligible persons, Medicaid will pay the cost of transportation to medical appointments. However, there are significant gaps in transportation services necessary to make the Most Integrated Setting goal feasible, particularly for rural residents.

Way2Go is a new community education program for finding, choosing and creating transportation options that support personal, community and environmental wellbeing. They gather and share information on the many different ways to get around, including tips on saving money, going green, staying healthy and promoting transportation equity. Way2Go is a program of Cornell Cooperative Extension of Tompkins County.

Coordinated Plan and Mobility Management Transportation gaps are best addressed through collaborative planning among stakeholders. The Federal government requires a Coordinated Public Transit- Human Services Transportation Plan before spending certain federal transportation funds. Many counties have used the Coordinated Plan process to address LTC and other senior transportation needs. Mobility management guides public investment in programs and projects. Coordinated transportation planning and mobility management can be used to develop new solutions for LTC transportation.

The transportation planners with the Tompkins County Department of Social Services recommend the following steps:

Support Older Drivers

- Add driver education to strengthen skills of older drivers.
- Transitioning from driver to passenger – assess skills and provide counseling on alternatives.

Support Health Care Givers

- Target education outreach on transportation alternatives to health care workers.
- Identify health care workers as a market for transportation supports and new services.

Support Volunteer Driver Transportation Programs

- Invest in trip reservation and management tools to support volunteer driver services.
- Develop paid volunteer driver programs with reasonable mileage reimbursement as an incentive to increase supply of drivers and vehicles for intra-county and out-of-county trips.

- Create task force to evaluate best practices for organizing and operating volunteer driver programs (including ITN America - Independent Transportation Network).

Invest in Coordinated Services

- Invest in information technology for Gadabout, taxi and other operators to schedule trip requests and manage operations, and broker rides.
- Create a single call center for customers to schedule trip requests.
- Invest in fuel efficient paratransit buses for Gadabout.
- Increase number of wheel chair accessible vehicles (e.g. taxis) available to the public on a 24/7 basis.

Increase Accessibility

- Increase availability of information and public education and outreach for all mobility alternatives through the County's Way2Go program.
- Create a network of travel trainers among agencies to support individuals learning to use transportation services.
- Support adding sidewalk and bicycle networks in existing communities and in future liveable community development.

Promising Trends

Some promising new trends have the potential to reduce the need for LTC, improve services, and empower care recipients and their caregivers.

Falls Prevention

Injuries related to falls are a leading cause of institutionalization and death in older adults. One in three adults 65 and older fall. While most result in minimal injury 20 to 30% suffer serious injury, particularly hip fractures and head injuries. Of those hospitalized with a hip fracture, 49% never return home or live independently again, and 25% die within one year. Loss of independence leads to institutionalization and escalating health care costs. Falls are a major public health concern.

In March 2005 The National Council on Aging in conjunction with The Archstone Foundation and The Home Safety Council issued an evidenced -based National Action Plan to prevent falls and fall-related injuries in older adults. In 2007 they issued a progress report (see; www.healthyagingprograms.org)

Additional sites that contain helpful information include:

Ithaca College Gerontology Institute learning modules "Falls Prevention" and "Safe at Home"
www.ithaca.edu/aging/training/

Center for Disease Control "Check for Safety: A Home Fall Prevention Checklist for Older Adults"
www.cdc.gov/npic/pub.res/toolkit/cksafety.pdf

Minnesota State Safety Council "Falls a Prevention Checklist"
www.mnsafetycouncil.org/seniorsafe/falls/index.cfm+

Falls prevention efforts nationwide
www.healthyagingprograms.org/contentasp?sectionid=98

Falls Prevention Center of Excellence www.stopfalls.org

Transitions of Care

Transitions of frail elders from home to (and from) institutional care environments, such as hospital and long-term care facilities, has a significant impact on their physical and emotional well-being. Eric Coleman (2004) defined transitional care as "a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location." These transitions often magnify the impact associated with the inadequacies in the health care system.

Each year older people experience over 13 million transitions from acute or rehabilitation facilities to home. In addition, acute care is now more apt to be delivered in long-term care settings. Care that was once provided in the hospital setting is now often provided in patient's homes, physician's offices, nursing homes and in other community settings. The discharge planning needs of older adults, which are influenced by race, culture, language differences, and urban or rural locations are complex and involve many different systems.

There have been a number of care transitions initiatives in Tompkins County, funded through the Community Health Foundation of Western & Central NY.

In addition, Tompkins County Office for the Aging was awarded an Aging & Disability Resource Center (ADRC) grant through AoA in 2009. This grant emphasizes the role of NY Connects/ Tompkins Care Connection in assisting with care transitions. Through the ADRC grant, a consumer navigator program will be developed with volunteers to assist frail elders in transitions of care between hospital, skilled nursing and home.

Transforming Nursing Home Care

There are several approaches to making care in facilities more homelike and inviting. Some promising initiatives are the Green House, Small House and Eden Alternative. These are being championed internationally by William Thomas who now happens to be a resident in Tompkins County. The information below is from the various websites.

Small House

The University of Minnesota has a Long-Term Care Resource Center which is engaged in studying the evolution of small-house nursing homes. http://www.hpm.umn.edu/ltcresourcecenter/research/green_houses.htm

Green House® is a trademarked version of a small-house nursing home, developed in concept by William Thomas, founder of the Eden Alternative. It is a model of skilled long-term care designed to transform traditional skilled nursing facilities into homes providing meaning and growth for the people who live and work in them. Instead of a large facility with many elderly residents, Green House projects create homes for 6-10 residents. Each resident gets a private bedroom and bath opening off a central area for cooking, eating and gathering. Nursing assistants play a much broader role in the care of patients. www.the**greenhouse**project.org

The Eden Alternative

The Eden Alternative is an international not-for-profit organization dedicated to transforming care environments into habitats for human beings that promote quality of life for all involved. Its principle-based philosophy empowers Care Partners to transform institutional approaches to care into the creation of a community where life is worth living. Our Vision: To eliminate loneliness, helplessness, and boredom.

They have a home-based model as well as a facility-based one. http://www.edenalt.org/

Community Cooperatives – some examples

"Share the Care" is an effort within Tompkins County's LGBT (lesbian, gay, bisexual, and transgender people) community to organize volunteers willing to provide assistance to others within the community who are seriously ill. Based on the book "Share the Care" by Capossela and Warnock, this is an effort to create unique caregiving teams when needed, sharing responsibilities and support, and avoiding burnout.

Beacon Hill (Boston) membership to pay for services that help people stay in their home, including geriatric care management, grocery shopping, walking groups, volunteers to help in your home, etc. Cost is $600/annually. See beaconhillvillage.org

Powerful Tools for Caregivers

Powerful Tools for Caregivers is a six-week psycho-social educational program, developed by Legacy Health System, for family and friends caring for adults who are suffering from long term disability.

The Tompkins County Office for the Aging leads a coalition to provide these programs. The original collaborators were: Hospicare & Palliative Care of Tompkins County, Cayuga Medical Center, Lifelong and Department of Social Services. There are 5 additional collaborators now, bringing the total to 10: Greater Ithaca Activities Center, Finger Lakes Independence Center, Cayuga Ridge Health and Residential Community, Cornell University and Binghamton University School of Social Work.

The class provides family caregivers with the skills and confidence to better care for themselves while caring for others. Many caregivers have found the class beneficial, including: those caring for a spouse or partner and adult children caring for parents. Class topics include:

- Taking Care of You
- Identifying and Reducing Personal Stress
- Communicating Feelings, Needs and Concerns
- Communicating in Challenging Situations
- Learning from Our Emotions and
- Mastering Caregiving Decisions.

Class participants report they:

- Are better at caring for themselves,
- Have fewer feelings of anger, guilt and depression,
- Have increased confidence and ability to cope with the demands of caregiving, and
- Take more advantage of community services.

Trained facilitators lead the classes using a standardized curriculum; class members receive The Caregiver Helpbook, which was developed specifically for the class.

There have been 96 graduates from the various Powerful Tools for Caregiving workshops offered in Tompkins County and an additional 6 trainers have completed the requirements to allow them to conduct the workshops. Four of the original trainers have qualified as Master Trainers. The increase in collaborators and trainers will allow more choices of venues and class times particularly in rural areas.

Chronic Disease Self-Management – Stanford University

The Chronic Disease Self-Management Program is a workshop given two and a half hours, once a week, for six weeks, in community settings such as senior centers, churches, libraries and hospitals. People with different chronic health problems attend together.

The Finger Lakes Independence Center and the Health Planning Council are collaborating to provide this program in Tompkins County. They have provided two series of workshops to date and plan to offer more in the upcoming year. They also are preparing to offer leader training in the spring 2010 to increase the capacity to provide this valuable service.

Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with a chronic diseases themselves. Subjects covered include: 1) techniques to deal with problems such as frustration, fatigue, pain and isolation, 2) appropriate exercise for maintaining and improving strength, flexibility, and endurance, 3) appropriate use of medications, 4) communicating effectively with family, friends, and health professionals, 5) nutrition, and, 6) how to evaluate new treatments.

Each participant in the workshop receives a copy of the companion book, *Living a Healthy Life With Chronic Conditions, 3rd Edition*, and an audio relaxation tape, *Time for Healing*.

It is the process in which the program is taught that makes it so effective. Classes are highly participative, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives.

The Self-Management Program does not conflict with existing programs or treatment. It is designed to enhance regular treatment and disease-specific education such as Better Breathers, cardiac rehabilitation, or diabetes instruction. In addition, many people have more than one chronic condition. The program is especially helpful for these people, as it gives them the skills to coordinate all the things needed to manage their health, as well as to help them keep active in their lives.

See the Appendix J for additional information about this program.

Advance Health Care Planning

Sharing Your Wishes is a local coalition of organizations and individuals whose goal is to encourage anyone 18 years or older to plan in advance for their health care in the event that they experience an illness or condition that prevents them from making or communicating their wishes. We know that planning in advance is the best way to ensure that their choices are known, understood, and honored.

The lead agency is the Health Planning Council, a program of the Human Services Coalition of Tompkins County. Founding partners include: Cayuga Medical Center at Ithaca, County Office for the Aging, Family & Children's Services, Finger Lakes Independence Center, Hospicare and Palliative Care Services, Ithaca College Gerontology Institute, Lifelong, Long Term Care Services and the Tompkins County Health Department. Other organizations and individuals are invited to join our community effort.

Thanks to the Community Health Foundation of Western and Central New York we had start-up funding from 2003 – 2006. They also provided extensive training and technical support. To support this improved health care

decision-making, our local coalition is implementing a multi-faceted approach. As time and funds permit we can:

1) Provide written materials to individuals and organizations,
   Also available on http://www.sharingyourwishes.org
2) Offer training for professionals and volunteers,
3) Make presentations and lead discussions, and
4) Meet with individuals (and their families) to facilitate their advance care planning.

As the Sharing Your Wishes materials note:

> Consider the many health care decisions that will be made over time for a person who is diagnosed with a progressive illness such as Alzheimer's disease or emphysema. Conversations can ensure that people's wishes are followed even when they are no longer able to speak for themselves.
>
> Most people today will live a long life. At various times, we may be less able to take care of ourselves or even to make health care decisions on our own. What if we are in an accident? What if we cannot speak? Will our loved ones know what we want? Will our wishes be honored?
>
> The most important thing we can do is to plan ahead and to talk with others about our wishes. It may not be easy for us to talk about how we want to live if we are in a life-threatening condition or gradual decline. But, avoiding the conversation may actually make it harder for everyone at a time of crisis. Planning ahead helps family and friends understand our wishes and can greatly reduce the uncertainty and anxiety for those who care about us.
>
> Advance health care planning is not just for care at the end of your life, but health care decisions throughout your life. Many of us think about advance care planning as an end of life issue, but most of us will benefit from having conversations with our loved ones and planning for our health care long before our last days of life.

Research has shown that terminally ill patients who talk over end-of-life treatments with their doctors spend less money and do not die any sooner but die more peacefully than those receiving aggressive care, researchers.

- Patients who have the discussion tend to opt for cheaper palliative care in a hospice or at home rather than costly treatments like emergency resuscitation, ventilators to breathe for them and movement to a hospital's intensive care unit.
- If half of the estimated 566,000 American adult cancer patients who died in 2008 had an end-of-life discussion, the projected savings would conservatively be $77 million, according to a report published in the Archives of Internal Medicine.
- U.S. policymakers are hoping to find ways to rein in soaring healthcare costs, and researchers said end-of-life care merits a close look.
- The one in 20 Medicare patients who die each year use up almost one-third of expenditures by Medicare, the government health insurance program for the elderly and disabled.
- One third of expenses in the last year of life are spent in the final month, according to the report, with aggressive treatments in the final month accounting for 80 percent of those costs.

- After interviewing the patients' caregivers and nurses, the researchers concluded that palliative care led to more comfortable deaths, and aggressive care did not prolong life.

(Source: Stern, Andrew. "Discussing end-of-life care lowers cost: U.S. Study." *Reuters Health* 9, Mar. 2009)

Other Advance Care Planning Resources

MOLST (Medical Orders for Life-Sustaining Treatment) This bright pink medical order form, signed by a NYS licensed physician, can help translate patient/resident goals and preferences into medical orders. It includes orders regarding: CPR (cardiopulmonary resuscitation); intubation and mechanical ventilation; artificial nutrition and hydration; future hospitalization and transfer; and antibiotics.

For more information see www.health.state.ny.us/professionals/patients/patient_rights/molst.

Excellus BlueCross/BlueShield has developed a very useful website (www.compassionandsupport.org) which has information about advance care planning, including MOLST. Dr. Patricia Bomba, Vice President and Medical Director, Geriatrics, Excellus, has provided leadership and direction as well as trained numerous people in these topics.

Hospice and Palliative Care Servicesa

Hospice provides professional medical care, pain management and emotional and spiritual support to people with a life expectancy of six months or less, should the disease continue its expected course. Patients need to have chosen to no longer receive curative treatment and agree to receive only care geared toward comfort and pain relief. Once certified for hospice care, Medicare and Medicaid (and many private insurance plans) will pay for selected items not normally covered by the regular programs, enhancing comfort and saving dollars. These items include the cost of medications related to the patient's hospice diagnosis and durable medical equipment such as electric beds, walkers, and wheelchairs.

Palliative care specializes in relieving the symptoms and stress of serious illness. Symptoms may be physical, emotional, or spiritual. The goal is to improve quality of life for the patient and their family. Palliative care may be appropriate at any point in an illness, from diagnosis on, and it can be provided at the same time as treatment that is meant to cure.

Hospicare and Palliative Care Services is the organization which provides these services in Tompkins County. Their team of staff and volunteers can help people in their home, in an area nursing home, or in the 6-bed Hospicare residence. They are one of the few free-standing hospice residences in NYS.

Hospicare & Palliative Care Services Utilization			
Overview	**2002**	**2005**	**2008**
Admissions	160	229	322
Unduplicated Patients	175	264	313
Bereavement Clients	--	355	326
Home Care, days provided	7,626	10,971	14,849
Volunteer Hours	--	3,375	4,344

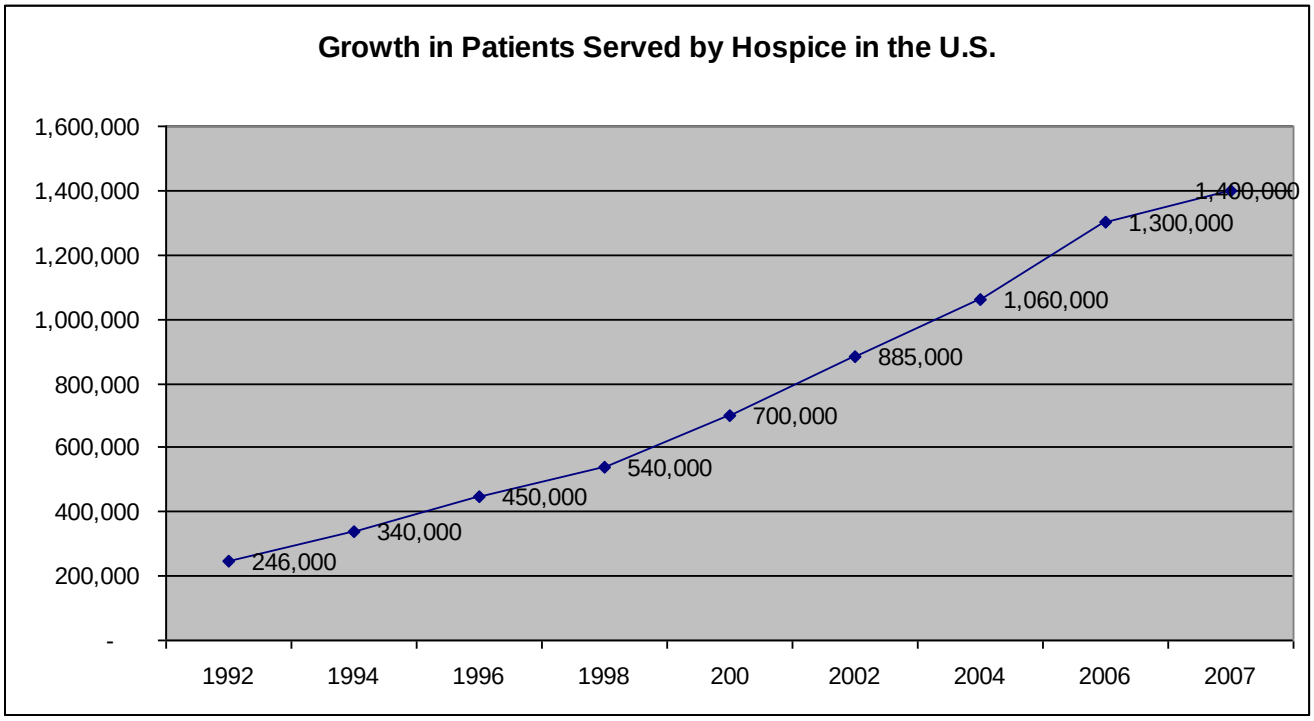
"Hospice Care Dramatically Reduces End-Of-Life Hospitalizations of Nursing Home Residents."

Researchers found that 26 percent of hospice and 44 percent of non-hospice nursing home residents were hospitalized in their last 30 days of life. Even after adjusting for confounding factors and selection bias, hospice patients were almost half as likely as non-hospice residents to be hospitalized. Hospice provides an alternative to aggressive curative care. Benefits include better palliative treatment that emphasizes physical, emotional, and spiritual pain relief for the patient and immediate family members.

Their finding were based on analysis of nursing home patient assessment records for 183,742 residents in 5 states, which they linked to the Medicare eligibility file that contains the Medicare beneficiary's date of death. A total of 14,615 residents enrolled in hospice while 169,127 residents did not. The study was supported by the Agency for Healthcare Research and Quality.

Agency for Healthcare Research and Quality 324 (2007)

For 2008, the National Hospice and Palliative Care Organization estimates that approximately 38.5% of all deaths in the United States were under the care of a hospice program.



How are services paid for and how much money is used?

Because about 80% of LTC services are provided by family and friends, the largest "payer" of services is donated time. The dramatic effect of this country's rapidly graying population is hitting home, with a New York State survey which found 1,923,778 caregivers providing 2+ billion hours of care per year at a $20+ billion cost saving to our health care system. (Source: 2004 National Family Caregivers Association)

In the United States, of dollars spent, long term care has been financed by the following sources:

	1990	2004
Private Individuals	48%	18.1%
Medicaid	45%	48.9%
Other	4%	2.6%
Medicare	2%	20.4%
Private Health Insurance	1%	19.9%

(Source: Health Care Financing Administration, U.S. Dept of Health and Human Services; Georgetown University Long Term Care Financing Project 2006)

The financing of long term care (LTC) services has shifted over the years and will likely undergo changes in the future. The largest government payer of long term care, Medicaid, is currently the focus of major restructuring efforts and will likely see some revision. Growing public and private sector pressures to reduce health care costs, combined with the rapidly increasing size of the elderly population, encourage us to look critically at supply and demand issues (both current and future) for Tompkins County.

Modes of health care delivery have often been driven and shaped by what Medicare and Medicaid will pay for, rather than by new and emerging needs. Emphasis has traditionally been on the delivery and payment of acute, episodic care. Changing disease patterns and demographics require a shift in emphasis to care for chronic, longer term disabilities.

Summary of Changes from 1997-2009

- Medicaid reimbursement rates have not kept pace with inflation
- COFA doubled the funds the county made available for EISEP (Expanded in-Home Services for the Elderly Program) 1999
- Financial eligibility for EPIC (Elderly Pharmaceutical Insurance Coverage) increased substantially 2000
- Medicare reimbursement moved from the Interim Payment System to the Prospective Payment System 2000
- Medicaid funding approved for Hospice Residence 2001
- Asset test for Medicaid home care services discontinued; asset test for skilled nursing facility payment continues 2004
- COFA and Lifelong awarded funding to provide community education and individual consultation about Medicare Part D prescription program 2005
- Long Term Care Insurance Resource Centers established by COFA and Lifelong; to promote use of LTC insurance provide increased opportunity to learn about LTC insurance 2005
- Medicare funding for home care services altered; CHHAs need to limit frequency and kinds of services offered to client to maintain fiscal viability 2007

Local nursing homes and home health agencies are dependent on third-party reimbursement because they do not have large endowments and the trend is toward fewer private pay patients. Long term care insurance policies are becoming more readily available to assist with nursing home and home health care payment but very few people to date have purchased this coverage.

The New York State legislature has recommended increasing personal responsibility to pay for LTC. Their central strategy has been to encourage the purchase of LTC insurance plans even though these plans are primarily cost-effective only for people in the upper-middle income range.

Medicaid Funding Issues

Medicare expenditures are paid 100% by the Federal government. Medicaid expenditures are shared by the Federal, state and local governments, with the percentage shares varying as follows:

	Federal	State	Local
Home Health Care			
Most people*	50%	25%	25%
Others**		50%	50%
Nursing Home Care	50%	40%	10%

* This includes most people on Medicaid receiving this type of care: those under 21, 65 and over, people related to Aid to Dependent Children or disabled in accordance with Social Security criteria

** This includes adults between 21 and 65 who do not fit the categories above.

Medicaid is the dominant payer for nursing homes. It pays for 78% of all nursing home days in the state. New York spent $6.2 billion in FY 2004 on nursing facilities alone, or about 15% of the total state budget. Combining the Personal Care Program, nursing facility payments, home health and other "waived" services (comprising long-term home care and adult day heath care), New York spent nearly $11.8 billion in fiscal year 2005 for long-term care services. (Source: Commission on Health Care Facilities. *A Plan to Stabilize and Strengthen New York's Health Care System*. Rep. New York, 2006)

The State continues to cut Medicaid reimbursement rates for LTC (and acute) services and has proposals to limit the number of hours of service. The Governor also has often proposed funding home health care through a block grant process but this has not yet passed; we could only support this approach if it assures access to safe, quality home care. Ntionally Medicaid pays about half of the cost of LTC.

Tompkins County Medicaid expenditures for long term care (from Fed/NYS/County) were:

	1996	2008
Skilled Nursing Facilities	$10,468,703	$13,039,101
Hospice	22,685	318,382
Personal Care	262,199	2,521,695
Home Health Services	365,973	497,093
Long Term Home Health Care Program (LTHHCP)	65,281	112,254
TOTAL	**$11,184,841**	**$16,488,525**

(Source: Tompkins County Department of Social Services)

It is helpful to keep in mind the cost of different levels of care. The following figures are approximately the cost of services in Tompkins County, (Source: Local agencies)

Type of Care	Cost per Day (or hour) 1997	Cost per Day (or hour) 2008
Skilled Nursing Facility	$130 - 150 regular rate $80 - 94 Medicaid rate	$220-250 regular rate $110-160 Medicaid rate
Adult Home	$42 average cost $28 SSI reimbursement	$100-250 private $32 SSI
Family-type Home	$35 - 90 approximately	$95-210
Adult Day Care - social - medical	 $30 $75 (now closed)	 $38 planned to open at Cayuga Ridge, 2010
Home Health Aide	$14 - 18 / hour	$22-27 per hour
Personal Care Aide, I and II	$12.50 - 16.50 / hour	$19-24 per hour

Services for Children – Tompkins County

Children over age three, with diagnosed developmental or intellectual disabilities, may be eligible for services through the Children with Special Care Needs program of the Tompkins County Health Department. They may also be eligible to participate in services through the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD). Two Medicaid Waivers are available for this population. The Care at Home Waiver (CAH) is designed for children with more significant health care needs. The Home and Community Based Waiver (HCBS) serves children with developmental disabilities through a variety of services including Service Coordination, Respite, Residential, Day, and In-home Services.

There are a variety of providers of these services including Broome Developmental Services, Franziska Racker Centers, Challenge, Groton Health Care and Unity House. In addition, children eligible for OMRDD services living at home with their family may access Family Support Services (FSS) services. These services include Behavior Support, Respite Reimbursement, an Autism Lending Library, and the Friendship Network.

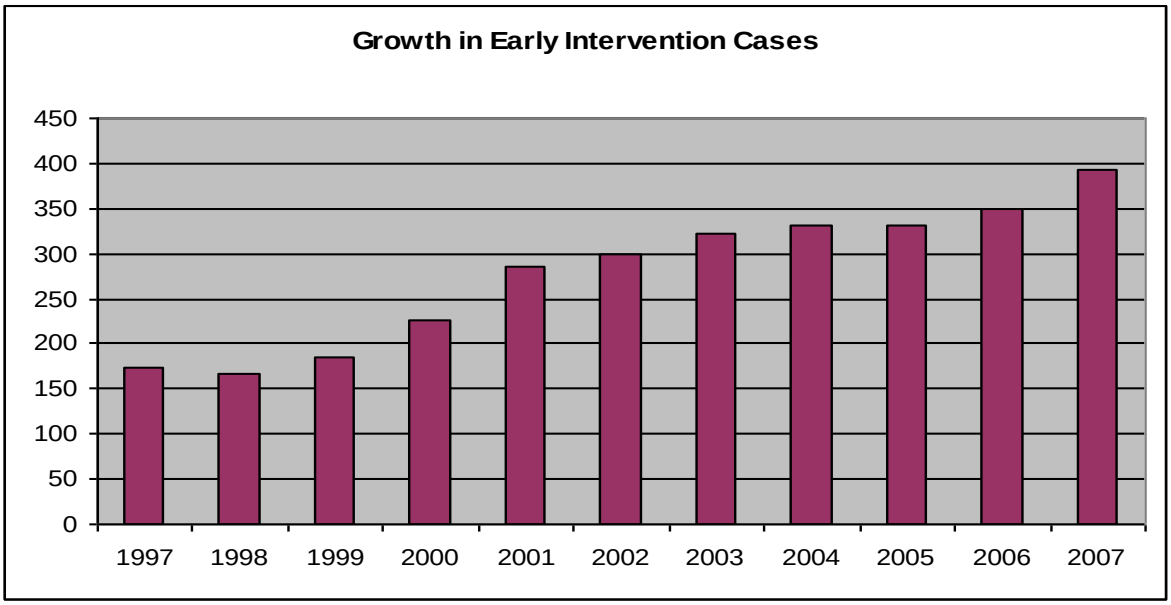
Funds to support LTC services to children include expenses reported in the 2008 annual report of the Tompkins County Health Department (TCHD). The Children with Special Care Needs program served 100 families in Tompkins County in 2008. They also provided 225 referrals to the Early Intervention program.

Children with Special Care Needs Budget—2007- TCHD

$ 1,341,847	Early Intervention
$ 4,351,168	Preschool Special Education
$ 8,000	Physically Handicapped Children's Program
$ 872,046	CSCN Administrative Budget (Includes salaries, fringes, computers, and other)
$ 6,573,061	**TOTAL**

Transportation Cost--2007

$ 73,264	Early Intervention Transportation Cost in 2007
$645,877	Preschool Special Education Transportation Cost in 2007
$719,141	**Total Division Costs**



Preschool Special Education Services Provided in 2006-2007 School year (TCHD)

Number	Cost	Type of Service
18	$12,480	Parent Counseling
6	$6,480	Psychologist
29	$163,039	Aide
4	$61,360	Interpreter
31	$85,581	Spec Ed Itinerant Teacher
33	$58,920	Physical Therapist
66	$115,740	Counseling
62	$10,260	Coordination
104	$1,957,921	Spec Ed--Tuition Programs
128	$208,500	Occupational Therapy
282	$680,220	Speech Therapy
8	$4,440	Audiological Services
11	$20,607	Other
	$3,385,548	**Total**

Early Intervention Services Provided in 2007 (TCHD)

Number	Cost	Type of Service
1	$96	Audiology
10	$960	Psychological
11	$748	Family Counseling
120	$11,072	Family Training
1,171	$87,188	Social Work
2,601	$175,931	Occupational Therapy
2,650	$179,953	Physical Therapy
2,904	$166,417	Special Instruction
7,768	$529,547	Speech/Language
17,236	**$1,151,912**	**Total**

Factors affecting future LTC need / demand

How long-term care arrangements actually evolve depends heavily on health status and future policy choices. For example, if utilization and illness patterns current in 1997 had continued, Tompkins County would have needed an estimated 122 more skilled nursing facility beds. Obviously this did not materialize.

As this report shows, the need for skilled nursing beds has been reduced but the need for various kinds of adult home beds has increased. Community-based services have increased, but more are needed. The community focus is changing to reducing the need for care and also offering support to informal caregivers; these are the best way to reduce cost of services as well as maintain our elderly and people with disabilities in the least restrictive setting.

Both the Robert Wood Johnson Foundation (RWJF) and the Urban Institute (UI) have devoted considerable research into future needs for long term care, particularly in light of the impending aging of the baby boomers. "Meeting the Future Long-Term Care Needs of the Baby Boomers" is a findings brief of the Robert Wood Johnson Foundation (July 2007). Their report identifies many of the factors that are also expected to be influencing our community. Excerpts from the report are below.

Current Patterns of Long Term Care

- Today, gender disparities exist in both the number of frail elderly needing help with the tasks of daily living and the informal caregivers who provide this assistance.
- Nearly two-thirds of older people with severe disabilities are female; women represent two thirds of all unpaid caregivers; and daughters account for 7 out of every 10 adult children who help their frail parents and approximately five of every six who assume primary responsibility for their personal care.
- Longterm care is a leading cause of catastrophic out-of-pocket costs for families and involves substantial government spending through Medicaid and Medicare.
- Few people carry longterm care insurance, which typically has high premiums. Even if they do, often this insurance has limited benefits that do not fully cover the cost of care.

Changes in Family Structure

- Recent changes in family structure may have significant consequences for the availability of unpaid long-term care.
- Declines in birth rates, decreases in family size and increases in divorce rates, childlessness rates, and the share of people who never marry all could potentially limit the availability of unpaid long-term care by family members.
- Additionally, as women have entered and stayed in the workforce their ability to provide care has been reduced.
- According to Johnson [lead researcher], "it is unclear whether men will fill the gap."

Changes in Disability Rates

- Even in the most optimistic, low-disability scenario, which assumes that disability rates fall by 1 percent per year, the size of the disabled population will grow by more than 50 percent between 2000 and 2040 and the number of disabled older adults for every adult age 25 to 64 will increase.
- Although evidence points to recent health improvements at older ages, there is no guarantee that these trends will continue. Disability associated with the rising prevalence of diabetes and obesity in the younger population might offset the future decline in disability rates at older ages.

Additional information is available from the Urban Institute (www.urban.org/url.cfm?ID=311451) Meeting the Long-Term Care Needs of the Baby Boomers; How Changing Families Will Affect Paid Helpers and Institutions

Another factor is that disability associated with Alzheimer's and related dementia may increase as health improvements in other areas result in more people living into their 80's and 90's.

How long term care arrangements actually evolve will depend heavily on future policy choices. On the national level, long term care policy intersects with labor policy and immigration policy. There is also a need to pay closer attention to the needs of informal caregivers. Policies that include time and payment mechanisms for respite care are important for supporting these individuals.

With current policies, rapid population growth will substantially boost the number of older people using paid long term care services. If future disability rates follow the intermediate growth scenario, the number receiving paid home care will more than double between 2000 and 2040, increasing from 2.2 million to 5.3 million. The number of older nursing home residents will also more than double over the period, increasing from 1.2 million to 2.7 million.

Efforts to promote private long term care insurance might add funding for future long term care services and increase the use of paid care. Medicaid and Medicare expansions could also make paid services more affordable. However, problems recruiting and retaining long term care workers could limit the availability of paid services and sharply raise costs.

Long Term Health Care Needs Assessment Recommendations

The recommendations in this report (pages 8 – 10) detail steps our community can take to provide needed services in a caring, cost-effective way. The Health Planning Council will work with many others to support implementation of the recommendations. We also encourage community agencies, legislators, foundations and current and potential providers of services to use these recommendations to help make informed funding and development decisions.

Appendix A **Definitions / Descriptions of Home Health Care Providers**

As of 7/7/09, the NYS Department of Health website lists the following agencies as being certified or licensed to provide home care services in Tompkins County.

Certified Home Health Agencies CHHA

Tompkins County Health Department
Visiting Nurse Service of Ithaca

Licensed Health Care Services Agencies LHCSA or LHHA

Agencies with offices in Tompkins County; those in bold are currently providing the majority of HHA, PCA services in our community.

Alternative Living Services, Inc. (Ithaca)
Bridges Cornell Heights Home Health (Ithaca)
Caregiver's (Ithaca)
Classen Home Health Associates (Ithaca)
Comfort Keepers (Syracuse)
Community Health and Home Care (Ithaca)
Family & Children's Services (Ithaca) (closed 6/30/09)
Redmoon Private Caregivers & Consultants (Ithaca)
Stafkings Healthcare Systems, Inc. (Ithaca)

The following 25 licensed agencies are also approved to serve Tompkins County.

Adirondack Manor Home Care Agency (Utica)
All Metro Health Care (Liverpool)
Alternative Living Services, Inc (Manlius)
Caregivers (Elmira)
Central New York Infusion Services, LLC (Dewitt)
Compassionate Care of Central New York, Inc. (Endicott)
Coram Healthcare Corporation of New York (Syracuse)
Critical Care Systems (East Syracuse)
Finger Lakes Home Care. Inc (Geneva)
Franciscan Health Support, Inc (Liverpool)
Gentiva Health Services (Binghamton)
Home Care for Cortland County, Inc. (Cortland)
Independent Health Care Services, Inc (Syracuse)
Interim Health Care Of Syracuse, Inc (Syracuse)
Interim Health Care of Binghamton, Inc. (Binghamton)
Lincare of New York, Inc (Clinton)
Maxim of New York, LLC (Syracuse)
Peregrine Home Care Strategies of New York, LLC (Syracuse)
Professional Home Care, Inc. (Vestal)
Serenity Home Care, Inc. (Mendon)
Sibley Nursing Personnel Service, Inc. (North Syracuse)
Sibley Nursing Personnel Service, Inc. (Binghamton)
Upstate Home Care (Syracuse)
Upstate Home Care (Clinton)

Appendix B **Descriptions and Training of PCA, HHS, and CNA**

Personal Care Assistant (PCA):
Light housework – making beds, dusting, vacuuming, cleaning, laundry, preparing meals. Personal care - dressing, grooming, walking, feeding, and other tasks.

Home Health Aide (HHA):
Assist with bathing, grooming and dressing, administer oral medications, assist with prescribed exercises, and perform housekeep-in and cooking.

Certified Nursing Assistant (CNA):
CNAs usually work in nursing homes or adult residences. Their responsibilities include answering patient's call lights, delivering messages, serving meals, making beds, helping patients eat, dress, and bathe, escorting patients to medical appointments, taking vital signs, observing patient's physical and mental conditions, and other tasks.

Training requirements for these direct care positions:

Personal Care Assistant (PCA):
40 hours, directed by a registered professional nurse, or a social worker, or home economist that has, at a minimum, a bachelor's degree in an area related to the delivery of human services or education. In-service training shall be provided, at a minimum, for three hours semiannually for each person providing personal care services to develop specialized skills or knowledge not included in basic training or to review or expand skills or knowledge included in basic training.

Home Health Aide (HHA):
NY Department of Health: 75 hours, including 16 hours of supervised practical training, Supervised practical training takes place in a laboratory, a patient's home, or a health care setting in which the trainee performs tasks on an individual (i.e. a volunteer or fellow student) under the supervision of a registered nurse (RN) or licensed practical nurse (LPN). A minimum of 50% of the supervised practical training must take place in a patient care setting. The training must be completed within 60 days of entering the training program

NY State Education Department: 95 hours: 65 hours of classroom training (which includes 20 hours of return demonstration), plus 30 hours of supervised clinical experience (10 hours of care must given to a patient in the home in 1-hour increments, supervised by a RN; 20 hours can be in a home care setting or in an acute care facility). Minimum age of 18 is recommended, 8th grade reading level recommended

Certified Nursing Assistant (CNA):
Federal minimum: 75 hours, including 16 hours of supervised practical training
New York State minimum: 100 hours, including 30 hours of supervised practical training

Those who are certified as CNAs may work as HHAs by completing a one-day competency training and testing.

Appendix C **Definitions of Residential Facilities**

This information was obtained from NYS Department of Health, CNYHSA, F&CS, and COFA list of Extended Care Housing Options. In addition to the services provided as part of the residence, people can purchase many other services.

Another helpful resource is the Continuing Care and Housing Guidebook produced by NYAHSA (*New York Association of Homes and Services for the Aging)* http://www.nyahsa.org/CCG/CCG.pdf (June 2007)

Senior Apartments
Housing designed or adapted, and maintained, for occupancy of elderly (usually over 62 years) and/or people with disabilities. Handicap accessible, one-level apartments, community lounge, increased security. Special social and health related programs are often provided to meet the needs and interests of resident. Most often have at least one meal a day as an option that can be purchased. No personal care. Often subsidized rent which often caps at 30% of income.

Enriched Housing
Provides residential care in community-integrated settings resembling independent housing units. The program provides or arranges the provision of room, and provides board, housekeeping, personal care and supervision. Resident needs to be self-directing.

Adult Homes
Private or semi-private room with centralized dining, housekeeping, laundry, and social programs plus supplementary personal care. Also protective oversight including medication management and nurse supervision (but not the medical or skilled services of a nursing home).
Not eligible for Medicaid reimbursement. These include:
Adult Care Facilities (more than 4 residents), and ($3,000 - $7,750/mo.)
(Longview, Kendal at Ithaca)
Family-type Board and Care Homes (up to 4 residents ($1,000 – 3,600/mo.)
(Deer Haven, Evergreen House, The Old Hundred)
(Under Department of Social Services jurisdiction.)

Assisted Living Program (Medicaid) in a residence (ALP)
Provides a combination of housing and personal care services. Clients receive 24 hr supervision, meals, room medication management. Clients would otherwise have to move to a nursing home. Medicaid only pays in NY-certified ALPs
None are currently available in the county but Cayuga Ridge Health and Residential Center is planning to open a 30 bed unit in 2010.
(Under Department of Health Jurisdiction)-

Assisted Living Residence (ALR)
Provides additional personal care services beyond basic package purchased. Difficult level to subsidize for those who can't afford private pay rates (those who need more than 3.75 hrs of personal care assistance but are not "nursing home eligible"). Brookdale's ClareBridge Cottage and Bridges At Cornell Heights now offer this level of care in Tompkins County; Longview has also applied for this designation.
(Under Department of Health Jurisdiction)

Enhanced Assisted Living Residence (EALR)
Residents may "age in place". Resident may be chronically chairfast, unable to transfer, need help to walk, be dependent on medical equipment, and/or have chronic unmanaged urinary or bowel incontinence, Currently none available in Tompkins County but Longview plans to offer 32 units in their new wing nearly completion.
(Under Department of Health Jurisdiction)

Special Needs Assisted Living Residence (SNALR)
For special populations such as dementia or memory care. Currently none in Tompkins County but Brookdale has applied for this classification for their Clare Bridge Cottage.
(Under Department of Health Jurisdiction)

Hospice Residence
Provide care to those with life limiting conditions. Currently Hospicare and Palliative Care Services of Tompkins County offer service in a 6 bed residence, at home and in SNF
(Under Department of Health jurisdiction)

Residential Health Care Facilities (SNF) (Nursing Homes)
Provides care for long term chronically ill patients and rehabilitative patients whose primary needs involve relatively complete assistance with activities of daily living (e.g. dressing, toileting, and ambulation) and/or essential skilled nursing care and medical supervision. Also available ombudsman and hospice programs. Sometimes eligible for Medicaid and Medicare reimbursement.
(Under Department of Health jurisdiction.) (Regular rates: $6,600 – $7,500/mo.)
(Medicaid rates: $3,300 - $4,800/mo.)

Lifecare Community
Provides a continuum of residential and health care services. They allow residents to continue living in the same complex as their housing and health care needs change. Life care communities usually offer apartments, cottages and group homes with a range of support options, as well as skilled nursing facilities. (Initial buyin and monthly maintenance)
(Health care facilities are under Department of Health jurisdiction)

Additional categories of care in past years

Domiciliary Care - A non-medical residential institution providing room, board, laundry, some form of personal care and, in some cases, recreational and social services. (Under DSS licensure) Not allowed to provide medical care as part of the direct services.
(Most domiciliary care facilities became adult homes.)

Health Related Facility - Provides lodging, board, and social and physical care. Residents' mental or physical conditions require care and services (above the level of room and board). This intermediate level of care was designed for persons who needed institutional services but did not require 24 hour nursing care.
(Most HRF beds became SNF, or nursing home, beds.)

Some HRF beds were known as Intermediate Care Facilities (ICF) or Individualized Residence Alternatives (IRA). These are part of the Mental Retardation/Developmental Disabilities program.

Appendix D

ACRONYMS

ADL	Activity of Daily Living (such as basic hygiene and self-care tasks, such as bathing, toileting, dressing or walking)
ALOC	Alternative Level of Care (refers to hospital care)
ALR	Assisted Living Residence
BOCES	Board of Cooperative Educational Services
CCRC	Continuing Care Residential Community
CHHA	Certified Home Health Agency
CNA	Certified Nursing Assistant
COFA	County Office for the Aging, Tompkins
CNYHSA	Central New York Health Systems Agency
DOH	Department of Health
DSS	Department of Social Services
EALR	Enhanced Assisted Living Residence
EISEP	Expanded in-Home Services for the Elderly Program
F&CS	Family and Children's Services
FLIC	Finger Lakes Independence Center
HHA	Home Health Aide
HIICAP	Health Insurance Information Counseling and Assistance Program
HPC	Health Planning Council of Tompkins County
IADL	Instrumental Activity of Daily Living (such as social functioning, shopping, house cleaning, cooking, and managing money)
LHCSA	Licensed Health Care Services Agency
LHHA	Licensed Home Health Agency
LTHHCP	Long Term Home Health Care Program
LTC	Long Term Care
PCA	Personal Care Aide
PERS	Personal Emergency Response System
SNALR	Special Needs Assisted Living Residence
SNF	Skilled Nursing Facility (nursing home)
SSI	Supplemental Security Income
TC	Tompkins County
RHCF	Residential Health Care Facility (nursing home)

Appendix E **Unmet Needs Survey Instrument** July, 2008

The Long Term Care Committee of the Health Planning Council is conducting an assessment of the long term health care needs of people in our community. As you may know, long term health care is defined as the assistance that individuals with a chronic illness or disability receive for an extended period of time to 1) help them perform the routine activities of daily life, such as bathing, dressing, ambulating, eating, and homemaking or 2) provide ongoing medical support.

We are requesting your input about the UNMET NEEDS for children, adults, and older adults who have illness and disabilities requiring long term health care.

Because your organization interacts with countless patients/clients every year, we believe you are in a good position to know about what services you are NOT able to find for your clients. We are surveying all senior residences, adult homes, residential health care facilities, home care agencies, community referral agencies, faith community leaders and representatives of senior groups. We will keep all individual responses confidential; reporting will be grouped by type of facility/agency. Please distribute to other staff members as appropriate; we're interested in a broad range of perspectives.

Survey of the Unmet Needs in Long Term Care Services for Tompkins County Residents

Your responses do not need to be in order of need or severity – just however you think of them. Please answer questions 1 through 3 for EACH unmet need you identify.

1. Describe client/family need that you have not been able to find in the community.

2. About how many people a year do you see that have this unmet need?

	0 - 4	5 - 24	25 - 49	50 - 99	100+
Ages 0-19	.	.	.	.	.
Ages 20-59	.	.	.	.	.
Ages 60+	.	.	.	.	.

3. What barriers exist to getting this service? (Check all that apply.)

	Cost	Not available	Transportation	Not enough staff	Client resistance	Regulatory roadblock
Ages 0-19	.	.	.	.	.	.
Ages 20-59	.	.	.	.	.	.
Ages 60+	.	.	.	.	.	.

Other barrier (please specify) _____

Feel free to copy this page as many times as you want.

Closing Questions

Any ideas on what would help meet the above identified unmet needs?
What could our community do that might improve the long term care system?

Appendix F

CASA (Community Alternative Systems Agency) **Association of New York State Presents:**

Restructuring Medicaid Home Care in New York State:
A CALL TO ACTION Winter 2009

http://broomecounty.net/broome/files/casa/pdfs/ACallToAction.pdf

Recommendations

As a national leader in home care, New York State has an opportunity to construct meaningful long term care system wide reform. The NYS CASA Association suggests the following recommendations be taken into consideration. To create the most effective and efficient quality care system it is important for the state, the local districts, consumers and providers to work as partners recognizing that local resources are either available or limited by the nature of the communities served.

1. The goals and measurable expected outcomes of long term care need to be clearly defined for all Medicaid funded care. The continuum of care includes State Plan Services, Waiver Programs, Assisted Living Programs and Nursing Homes. Evidence-based means of achieving goals and measurable outcomes need to be researched and developed for the entire continuum.

2. The New York State departments of Health, Aging, Mental Retardation and Developmental Disabilities and Mental Health oversee a myriad of community based programs. These agencies must align their vision, culture and philosophies.

Conflicting values and practices among state agencies are reflected at the local level. NYS offers very generous state plan services, as well as services provided by the State Office for the Aging and nine waiver programs. The regulations governing these programs are derived from the differing philosophies of these competing state agencies. Do we respond to peoples' needs or wants? Are Medicaid dollars to be used to address medically related conditions or to meet people's need and desire for socialization? Personal Care Service Program regulations were designed to address the need for basic task related care due to disabling physical conditions; the program is also accessed by those with disabling mental health conditions and developmental disabilities.

3. **Data needs to be collected, analyzed and widely disseminated**.

Before creating any new system of care the state needs to take a step back and collect some statistics on who is being served and how. As noted in the Governor's budget, "Fewer people are getting services, but the cost per person is rising sharply due to the increased level and costs of the services provided."

- What are the current administrative costs of operating the Medicaid personal care program via a county system of service delivery?
- What are the projected administrative costs for operating the Medicaid personal care program via non-governmental agencies?
- Who is being served?
- What types of chronic conditions do they have?
- What are the services they are receiving?
- How many programs are people participating in (HCBW, TBI, CAH, NHTDW, OMRDD, PCSP, PDN)?
- Are services being duplicated?
- Do the services conflict?
- What types of outcomes can we expect for the money we are paying for the care?
- What is the average length of stay in Medicaid Personal Care Programs?
- How often do consumers transition between care sites?
- How does the need for care change over time?
- How many have a diagnosed mental health problem?
- How many have drug and alcohol problems?

- How many are developmentally disabled?
- What is the range of ages of people in the Personal Care Program county by county?
- What impact has the introduction of waivers had on Medicaid personal care (state plan) expenditures?
- Where does the money go?
- Who benefits from the system in its current form?
- Who resides in the households of people receiving personal care?
- What are the average hours of service delivery per week? By program? By disease process? By age category?

There are many unanswered questions when it comes to Medicaid personal care in NYS. Without an understanding of who is currently being served and how the population has changed and will change over the years, it is difficult to determine how best to restructure the system.

4. PCSP Regulatory Reform.
The regulations governing personal care services (505.14) emphasize that services are provided to assist people with personal hygiene, nutritional and environmental tasks. These services are related to a medical condition and physician orders must be obtained to verify that the person needs care. The regulations provide little guidance in determining the number of hours of care a person might receive, particularly in the case of disabled children, and have never been revised to include Consumer Directed Care. In fact, in NYS there is essentially no limit on the number of personal care hours a person might receive. The NYS Personal Care Services regulations need to be revised to clarify the allowed Medicaid funded care a client can receive.

5. Provide substantive and ongoing training to those administering all Medicaid home care programs and to State Fair Hearing staff.
Personal care services, operated by local social service districts or local Offices for Aging, are woven into the fabric of their communities. If the program is not delivered "consistently throughout the state" it goes beyond districts "not cooperating." Staff works on complex social problems presented by consumers by accessing the local resources which are often unique to each community and limited by the availability of local resources. The PCSP, the largest home care program in the United States, offers absolutely no training from the state level to the local level. At a minimum, a training program that addresses the need for consistent assessments should be offered on an annual basis in regard to: assessment, care planning, and case management.

6. Provide substantive and consistent public education/orientation to households applying for in home care on their rights and responsibilities regarding the program's services.
Very few households have any experience in directing the work of others in their home. This can lead to underutilization of the personal care aide, or in placing unreasonable demands upon the aide. Statewide orientation of the consumers of personal care and their family members can help reinforce a strength based approach to designing and executing a care plan, and set clear expectations for performance.

7. Create the resources and tools needed at the local level for service provision.
We support the development of a statewide assessment tool. NYS also needs to provide the resources at the local level to efficiently and effectively deliver home care. Housing stock in NYS is aging and often not accessible. The state should promote development of new housing that emphasizes livable components. Localities are essential in collecting data on client characteristics, outcomes and expenditures; however they are woefully lacking in computer resources.

8. Create a state service corps for aides.
Unless and until aides are paid a decent living wage with benefits, we will always have problems recruiting and retaining aides. If the state and federal governments continue to allow profits to go to agencies without paying the work force, then a service corps for aides should be created. This could be tied to college education tuition forgiveness. College students could work during the school year and summers or even full time after college for

a year or two to pay back their college loans. This would be one way to expose young adults to health professions or social work.

9. Once the state has created the mechanisms and the tools to move the system forward, create opportunities that allow counties to cross county lines to consolidate the intake and assessment process for Medicaid funded care.
Counties could create MOUs with neighboring counties to share resources in program administration and delivery. These collaborations will depend on the counties involved; those that can benefit due to their geographic or regional situations. There are counties throughout the state with urban cores that act as market centers to neighboring rural counties. These **naturally** occurring market areas could form consortiums to partner in the delivery of service.

In support of these recommendations, the NYS CASA Association will use the rest of this paper to describe the environment we currently operate in, the lessons learned, barriers and obstacles and case studies.

Appendix G

County Office for the Aging:

Improving Paraprofessional Training and Retention in Tompkins County
Progress Report Fall, 2009

The goals of Tompkins County's Fellow's Action Network (FAN) grant through the Community Health Foundation of Western & Central NY are to increase the ranks of the long term care workforce in Central New York, and to equip organizations and facilities with tools to improve the retention rates of direct care staff. Grant funds were used to hire a part-time temporary Project Assistant, Alexandra Clinton, to provide administrative and program support to carry out the grant deliverables.

Community Collaboration

The Long Term Care Workforce Initiative publicly kicked off in Tompkins County at a meeting of stakeholders and providers convened by the Office for the Aging on March 13, 2009. Over 50 providers attended this initial meeting. The presentation on March 13 served to introduce the goals of the grant and to solicit advice and feedback on how best to proceed. From this larger group, two smaller working groups were formed: a Training Working group and a Retention Working group, to meet and discuss each aspect of the grant. These two groups met separately for two months: March 26 and April 23, and then consolidated into one working group after the April meeting. This condensed group met again in May, July, and September. A meeting was held in June for those who were interested in participating in the SUNY consortium grant for CNA and HHA trainings, and a mid-year steering committee meeting was held on August 13 to discuss the progress we had made to date and to discuss the best way to proceed with the retention piece. A special meeting was held on September 29 to introduce local home care agencies to an opportunity to participate in a Retention Specialist program developed by the Cornell Institute for Translational Research on Aging (CITRA). Copies of the minutes from these meetings are included with this report.

Regular monthly meetings have fostered collaboration and a sense of community spirit and support for a variety of local organizations involved in providing or supporting long term care. These organizations cross various sectors and include representatives from educational institutions: TST BOCES, Ithaca College Gerontology Institute (ICGI) and the Cornell Institute for Translational Research on Aging (CITRA); non-profit organizations: the Health Planning Council of Tompkins County, the Central New York Area Health Education Center (CNYAHEC), the Community Foundation Women's Fund, and the Finger Lakes Independence Center (FLIC); for-profit agencies: Cayuga Medical Center, local home health providers and nursing homes; and governmental agencies: the County Office for the Aging (COFA), Tompkins County Health Department (TCHD), Tompkins County Department of Social Services (DSS), and others.

Bringing these agencies and organizations together proved to be invaluable – ***several members of the initiative mentioned that they appreciate the opportunity to sit with other home health agencies as well as all of the above-mentioned groups, bring their needs and concerns to the table, and work on common challenges.*** These meetings have led to productive discussions and positive feedback – one agency commented that she appreciates simply having the opportunity to come together with other local agencies and organizations to discuss issues facing the industry.

Training

Several options for community aide training were researched and considered, including offering Home Health Aide training though BOCES and the State Education Department. Ultimately, the option that materialized as the most efficient and cost effective was utilizing one local agency, Comfort Keepers, as a Department of Health-approved training site for the community home health aide (HHA) trainings. Comfort Keepers set up collaborative agreements allowing individuals from other agencies to be trained through their program. ***Hence,***

the goal of establishing ongoing community aide training in Tompkins County was met: home health aide trainings are now offered regularly through this provider.

Additionally, a connection with Tompkins Cortland Community College (TC3) culminated in the development of a series of training sessions for both HHAs and CNAs. A representative from TC3.Biz presented the group with an opportunity to apply for a grant from the State University of New York (SUNY) that could be used to help fund trainings for health care workers. The application was submitted by the group with TC3.Biz coordinating the effort, and ***in August, 2009, we received $50,000 in grant funds to subsidize direct care worker trainings in Tompkins County***. ***By June of 2010, a total of 32 CNAs and 40 HHAs will be licensed and certified using this funding.***

Four HHA trainings are scheduled at Comfort Keepers. The clinical portion of the class will be held at Sterling House. The classes will be held full time on the following dates:

October 26 – November 11, 2009	March 15 - 31, 2010
January 4 – 20, 2010	May 17 – June 2, 2010

Four CNA trainings have been planned, and they will take place at Lakeside Nursing and Rehabilitation Center. A trainer from TST BOCES will lead the sessions. The classes will be held full time and will run for five weeks. The current schedule is as follows:

October 12- November 13, 2009	March 8 – April 10, 2010
January 4 – February 6, 2010	May 10 – June 12, 2010

Communication/Customer Service Skills training
A training on communication and customer service skills specific to health care is being planned for March/April 2010 with Rich Gallagher. Details on the exact dates and times are being determined.

Retention

The Long Term Care Workforce group explored various approaches to improving retention, including the OPEN Model, used in Western Michigan. At our Working Group meeting in March, we hosted a conference call with Carol Helsel, the coordinator of the OPEN Program, to discuss how the program operates. The OPEN Model calls for a dedicated, shared case manager to provide on-site support to direct care workers to address issues and concerns that would prevent the workers from performing their jobs. One obstacle is that without some form of subsidy (via grant funds, for example), agencies would need to provide funding for a program that is currently untested in Tompkins County.

At the Steering Committee meeting on August 13, Rhoda Meador from CITRA presented the Retention Specialist program. This program has been rigorously tested in nursing homes, and has been found to be an effective retention strategy. CITRA is currently pilot testing the Retention Specialist training in the home care industry through a grant with the NYS Home Care Providers Association. Our Long Term Care Workforce initiative is now partnering with CITRA to include local agencies in this training.

An informational breakfast for interested agencies was held on September 29 and was well-attended. The one-day pilot training was held October 28th at Kendal of Ithaca, and was attended by representatives from Redmoon, Visiting Nurse Services, Community Health and Home Care (CHHC), the Tompkins County Health Department, CareGivers, Hospicare, and Comfort Keepers. May agencies had more than one representative in attendance, so a total of fourteen individuals were trained at the pilot training. Discussion was lively, enthusiastic, and constructive. The one-day training is followed by a series of webinars: one weekly for four weeks, followed by webinars once per month for six months.

By the end of the CHF grant cycle, and in partnership with Dr. Meador and CITRA, we expect to offer Retention Specialist training to all local home health agencies and nursing homes.

Long Term Provider Needs Assessment

Through this grant, we implemented a survey of home health providers in Tompkins County, including home health agencies, nursing homes, and hospice. The response rate was acceptable (11 respondents out of 18 for a response rate of 61%), however, due to the small sample size, it was difficult to form many firm conclusions from the data we received.

Career Ladder/Lattice

We are continuing to pursue ways in which to develop a universal direct care worker title that would allow direct care workers to advance efficiently from one career tier to the next. We had been following the progress of Project CODA, a group in Erie and Niagara Counties that was researching ways in which to streamline the many titles used in the direct care workforce and create a meaningful career path for direct care workers. Alexandra Clinton attended the two meetings they have held so far (one on April 23 and another on July 22) by teleconference. As of the July 22 meeting, Project CODA had decided to pursue a different direction and focus more on direct care worker training.

At the Steering Committee meeting on August 13, it was decided that the scope of this issue was too great for our group to take on alone; however, we have expressed our interest in this issue to both Project CODA and PHI and will follow any progress.

Recruitment

We have updated and expanded a booklet for potential direct care workers entitled "Careers in Caring." This booklet will be distributed at career fairs, the Central New York Area Health Education Center, high school career/counseling offices, Tompkins Workforce New York, and other appropriate locations within Tompkins County. A copy of this booklet is on the COFA web site, www.tompkins-co.org/cofa/

Appendix H

Older Adult Committee
C/O Tompkins County Office for the Aging
320 N Tioga St
Ithaca, NY 14850
November 1, 2007

Michael F. Hogan, PhD
New York State Commissioner of Mental Health
44 Holland Avenue
Albany, New York 12229

Dear Dr. Hogan;

We, the Older Adult Committee, a focus group of the Mental Health Subcommittee of the Tompkins County Community Mental Health Services Board, are dedicated to identifying and resolving gaps in services to older adults with mental illness in Tompkins County. We are concerned about the limitations in mental health services to older adults, particularly those with the dual diagnoses of dementia and mental illness.

- Service providers in Ithaca and in the upstate area frequently experience difficulties in obtaining inpatient and inpatient psychiatric support for geriatric dementia. These problems include the following:

- Psychiatric facilities are ill-equipped to provide care to geriatric patients requiring nursing and activities of daily living assistance, and are denied adequate reimbursement when they do provide care for this population.

- Geriatric residential facilities are often unable to access outpatient psychiatric support to provide care for residents with severe behavioral issues, and are forbidden by regulation to retain residents who become a danger to themselves or others.

- Mental health providers often lack experience with geriatric issues, and are ill-equipped to treat individuals with dementia.

- Long Term Care providers are not equipped to handle residents with severe psychosis or behavioral issues.

- Older adult patients and their families face a system that is unable to provide the support and care that they need.

- Medicare regulations do not cover therapy for residents with dementia due to an assumption that the demented resident cannot benefit from counseling or other therapeutic programs, an assumption that is unwarranted in many cases.

To put this in a larger perspective, 20% of older adults have a diagnosable mental disorder such as dementia, depression, anxiety or schizophrenia. Virtually all of them also have chronic health conditions. About half of those over the age of 85 have a diagnosis of dementia, and this age group continues to grow. To provide adequate care to older adults we must integrate health, behavioral health, and aging services.

A recent situation underscored the many gaps in available services. This involved an Adult Home resident diagnosed with dementia with psychotic features. The resident's Health Care Proxy noted a progressive gait disturbance, a known side effect of a psychotropic medication she was taking, and requested that the medication be discontinued. After weeks without this medication, the resident's mental status and behavior gradually deteriorated. She became increasingly aggressive and violent toward others.

When the resident's behavior escalated to the point where she endangered other residents, tried to elope, and injured a staff member, she exceeded regulatory retention criteria for the Adult Home. The facility transported this individual to the local Medical Center's Emergency Room in the hope that she would be admitted for behavioral stabilization. After the resident spent several hours in the emergency room, the Medical Center informed the Adult Home that the resident could not be

admitted to the Medical Center's psychiatric unit. She was deemed inappropriate due to her dementia and her presumed inability to benefit from group psychotherapy. She was discharged back to the Adult Home in the care of her son.

The Medical Center informed the Adult Home that obstacles to admission to the inpatient psychiatric unit included ineligibility for Medicare reimbursement for a patient with a diagnosis of dementia, the anticipated long term stay, and the fear that no appropriate discharge option from the psychiatric unit would be identified. Therefore the Medical Center would not accept her as an inpatient to stabilize her psychotropic medication.

The Adult Home then contacted Rome Memorial Hospital's Senior Behavioral Health Unit, who stated that that they cannot admit patients with advanced Alzheimer's dementia, as such patients would not benefit from their program, even though medication stabilization was the goal of admission. There was an implication that they could not get Medicare reimbursement for a diagnosis of dementia.

The Adult Home contacted a local skilled nursing facility which was planning to open a behavioral unit in the near future, yet they stated that if the resident could not participate in group psychotherapy this would not be an appropriate admission.

After much advocacy, the Medical Center's psychiatric unit did admit the resident, and was able to stabilize her with psychotropic medications; however, they were not prepared to treat her chronic medical conditions and need for personal care. Urinary incontinence was not addressed adequately, she was not encouraged to ambulate, and her meat was not cut up so that she could eat it (knives were not provided due to safety concerns). To complicate matters, the other young psychotic patients were frightening to this client. As they had anticipated, the Medical Center faced delays in discharging the resident, but finally the family was able to find placement in a residential facility by hiring 24-hour private care until a dementia-specific locked Adult Home had an available room. The resident presently resides in the dementia-specific locked Adult Home with additional private aide service, at considerable expense to the family.

The situation described here is not unique. Families who struggle with the behavior problems of their demented elders have few resources to support them. Psychiatric facilities are ill-equipped to provide care to geriatric patients requiring nursing and ADL assistance, and are denied adequate reimbursement when they do provide care for this population. Geriatric residential facilities are often unable to access outpatient psychiatric support to provide care for residents with severe behavioral issues, and are forbidden by regulation to retain residents who become a danger to themselves and others. Mental health providers often lack experience with geriatric issues and are reluctant to treat individuals with dementia. Health providers are not equipped to handle residents with severe psychosis or behavioral issues. Older adult patients and their families face a system that is unable to provide the support and care that they need.

We appreciate your consideration in this matter. We look forward to receiving your response regarding actions being taken to resolves these issues.

Sincerely,

Marilyn Roberts Chase, Chair
cc: state and county legislators (list)

Appendix I

Draft MISCC Plan http://www.omr.state.ny.us/MISCC/hp_miscc_DRAFT_2010-11.pdf

Chapter 551 of the Laws of 2002 created the Most Integrated Setting Coordinating Council (MISCC). The MISCC statute calls for the "development and implementation of a plan to reasonably accommodate the desire of people of all ages with disabilities to avoid institutionalization and be appropriately place in the most integrated setting possible." The following MISCC Plan covers the two year period of 2010-2011. It creates measurable agency specific housing, employment, transportation, long term care and community based treatment goals which will assist New Yorkers with disabilities to live in the most integrated settings. The Long Term Care section is below.

MISCC Long Term Care Goals

Access to Community Care Identify specific priorities that increase access to community care including: waivered programs; nonmedical services; health and safety; consistency of Medicaid Program implementation; dissemination of public health information; community education; waiting list issues; and supports to avoid overinstitutionalization.

Quality Assurance and Accountability Identify specific issues that improve quality assurance and accountability to ensure that services are provided in the most integrated setting.

Transitions of Care Address issues across the continuum of health care needs including: access to services in hospitals; additional forms of respite; discharge planning; care coordination models; assessment tools; facilitated waiver enrollment; and presumptive eligibility.

Barriers Identify specific barriers that prevent people with disabilities from transitioning to, and living in, the most integrated setting.

Implementation Actions

- Creation of a long term care work plan that addresses the following areas: increased access to community care, improved quality assurance and accountability of health programs, transition of care from segregated to integrated settings, increased workforce opportunities and elimination of barriers that prevent individuals with disabilities from living in the most integrated settings.
- Implement consumer direction as a service delivery option within NYSOFA's Expanded In-Home Services for the Elderly Program and the Community Services for the Elderly Program.
- Reach individuals not eligible for Medicaid, but who are at high risk of nursing home placement and spending all their income and assets to the Medicaid level and help those individuals maintain their independence and remain in their communities by offering consumer directed models of care, which allow individuals more involvement and control over the types of services, supports, and benefits they receive, and the manner in which these services are delivered through a federal Nursing Home Diversion Modernization Grant and a federal Community Living Program Grant.
- Implement the Community Navigator Program through a federal Aging and Disability Resource Center Grant to: improve compliance with post acute primary medical care appointments and planned medical treatments; improve access to needed medical support services in the community; improve access to needed non-medical support services in the community; improve access to prescribed medications; improve compliance with taking prescribed medications; improve access to needed food and household supplies; reduce returns to an emergency room; reduce hospital re-admissions; and improve quality of life for older adults with disabilities in the community following a hospital stay.
- Form a statewide, cross-disability, intergenerational caregiver coalition that will act as a united voice on behalf of caregivers to advocate for public policy, legislation, and needed programmatic changes that support caregivers through the New York State Family Caregiver Council.

- Educate, support, and empower caregivers to be better caregivers by teaching them practical skills to: help them manage their caregiving responsibilities; understand their roles and gain confidence in their abilities; learn the importance of caring for themselves and stress reduction; learn how to better care for their loved ones; and learn how to plan for the future through the New York Elder Caregiver Support Program.
- Provide one stop access to free, objective and comprehensive information and assistance on local long term care programs, services and resources through the NYConnects Program.
- The vigorous advocacy activities of the Protection and Advocacy Programs in representing the interests of persons with disabilities seeking least restrictive placements pursuant to their rights under Olmstead and the ADA will continue to be supported. Specific outcome measures will be reflected in their programs' annual Reports.

Appendix J

Chronic Disease Self-Management Program

Fact Sheet From: http://patienteducation.stanford.edu/materials/

The Chronic Disease Self-Management Program is a workshop given two and a half hours, once a week, for six weeks, in community settings such as senior centers, churches, libraries and hospitals. People with different chronic health problems attend together. Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with a chronic diseases themselves.

Subjects covered include: 1) techniques to deal with problems such as frustration, fatigue, pain and isolation, 2) appropriate exercise for maintaining and improving strength, flexibility, and endurance, 3) appropriate use of medications, 4) communicating effectively with family, friends, and health professionals, 5) nutrition, and, 6) how to evaluate new treatments.

Each participant in the workshop receives a copy of the companion book, *Living a Healthy Life With Chronic Conditions, 3rd Edition*, and an audio relaxation tape, *Time for Healing*.*

It is the process in which the program is taught that makes it effective. Classes are highly participative, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives.

Does the Program replace existing programs and treatments?

The Self-Management Program will not conflict with existing programs or treatment. It is designed to enhance regular treatment and disease-specific education such as Better Breathers, cardiac rehabilitation, or diabetes instruction. In addition, many people have more than one chronic condition. The program is especially helpful for these people, as it gives them the skills to coordinate all the things needed to manage their health, as well as to help them keep active in their lives.

How was the Program developed?

The Division of Family and Community Medicine in the School of Medicine at Stanford University received a five year research grant from the federal Agency for Health Care Research and Policy and the State of California Tobacco-Related Diseases office. The purpose of the research was to develop and evaluate, through a randomized controlled trial, a community-based self-management program that assists people with chronic illness. The study was completed in 1996.

The research project had several investigators: Halsted Holman, M.D., Stanford Professor of Medicine; Kate Lorig, Dr.P.H., Stanford Professor of Medicine; David Sobel, M.D., Regional Director of Patient Education for the Northern California Kaiser Permanente Medical Care Program; Albert Bandura, Ph.D., Stanford Professor of Psychology; and Byron Brown, Jr., Ph.D., Stanford Professor of Health Research and Policy. The Program was written by Dr. Lorig, Virginia González, M.P.H., and Diana Laurent, M.P.H., all of the Stanford Patient Education Research Center. Ms. González and Ms. Laurent also served as integral members of the research team.

The process of the program was based on the experience of the investigators and others with self-efficacy, the confidence one has that he or she can master a new skill or affect one's own health. The content of the workshop was the result of focus groups with people with chronic disease, in which the participants discussed which content areas were the most important for them.

How was the Program evaluated?

Over 1,000 people with heart disease, lung disease, stroke or arthritis participated in a randomized, controlled test of the Program, and were followed for up to three years. We looked for changes in many areas: health status

(disability, social/role limitations, pain and physical discomfort, energy/fatigue, shortness of breath, psychological well-being/distress, depression, health distress, self-rated general health), health care utilization (visits to physicians, visits to emergency department, hospital stays, and nights in hospital), self-efficacy (confidence to perform self-management behaviors, confidence to manage disease in general, confidence to achieve outcomes), and self-management behaviors (exercise, cognitive symptom management, mental stress management/relaxation, use of community resources, communication with physician, and advance directives).**

What were the results?

Subjects who took the Program, when compared to those who did not, demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. They also spent fewer days in the hospital, and there was also a trend toward fewer outpatients visits and hospitalizations. These data yield a cost to savings ratio of approximately 1:4. Many of these results persist for as long as three years.***

How can my facility offer the Program?

Trainings for representatives of health care organizations are 4½ days. There are 3-4 trainings scheduled at Stanford University each year.

*Both *Living a Healthy Life With Chronic Conditions (3rd edition)* by Lorig, Holman, Sobel, Laurent, González and Minor (2006), and the *Time for Healing* audio tape by Catherine Regan can be ordered from Bull Publishing.

**A complete report on the measures used and their psychometric properties can be found in *Outcome Measures for Health Education and Other Health Care Interventions*, by Lorig, Stewart, Ritter, González, Laurent and Lynch, Sage Publications, 1996.

***Outcome data reported in:
Lorig KR, Sobel DS, Stewart AL, Brown Jr BW, Ritter PL, González VM, Laurent DD, Holman HR. Evidence suggesting that a chronic disease self-management program can improve health status while reducing utilization and costs: A randomized trial. *Medical Care*, 37(1):5-14, 1999.
Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW, Bandura A, González VM, Laurent DD, Holman HR. Chronic Disease Self-Management Program: 2-Year Health Status and Health Care Utilization Outcomes. *Medical Care*, 39(11),1217-1223, 2001.
In HMO setting: Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a Self-Management Program on Patients with Chronic Disease. *Effective Clinical Practice*, 4(6),256-262, 2001.