Improving Outcomes for People in Tompkins County

By Strengthening the Long Term Care System

Executive Summary

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
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}

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<th>Estimates of Disability – Tompkins County – 2000 Census</th>
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<tr>
<td>Non-institutionalized, Civilian Persons – ages 5 and over (Does not include 350+ people who live in nursing homes)</td>
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<tr>
<td>5 to 20</td>
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<td>With a disability</td>
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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.
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.

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<th>Percentage of disability group estimates by age (National data)</th>
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<tr>
<td>Age 65–74 Disabled</td>
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<td>Age 75–84 Disabled</td>
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<td>Age 85+ Disabled</td>
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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 accessed on www.hsctc.org, click on health.