



Advocating for Older Adults of Today and Tomorrow

For Release:
January 16, 2008

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Thousands respond to UConn Health Center study: Long-Term Care Research Reveals Residents, State are Unprepared

HARTFORD—Most of the 6,268 Connecticut residents responding to a statewide survey believe they will need long-term care someday but many aren't adequately planning ahead because they don't fully understand what long-term care is, who needs it, how much it costs or what choices are available to them.

“Many people erroneously believe long-term care refers exclusively to nursing home care, primarily for older adults, or to insurance,” says Dr. Julie Robison, a leader of the University of Connecticut Health Center's Center on Aging research team that conducted the study.

In fact, long-term care encompasses the array of services needed for extended periods by people of all ages who need help due to a disability or chronic illness. People may need assistance with the basic functions of daily living such as eating, dressing, bathing, transportation, managing finances and shopping or total, 24-hour skilled care.

“As the demand and costs for services and supports increase, the public's need for information, combined with a highly fragmented long-term care delivery system, call for educational outreach and fundamental systemic change,” Robison says.

Long-term care is provided in diverse settings including private homes, adult day care centers, nursing homes, assisted living and intermediate care facilities, psychiatric and chronic disease hospitals and facilities for persons with developmental disabilities. It may also be provided in homeless shelters and prisons.

“It's no exaggeration to say that nearly every person in Connecticut will be affected by the need for long-term care at some point in their lives, either as a caregiver, a person who must arrange help for a loved one, or who personally needs assistance,” Robison says. “Informal” caregivers—family and friends who provide care without pay—are the primary source of long-term care, she says.

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The Connecticut Long-Term Care Needs Assessment, the first in more than 20 years, was authorized by the 2006 General Assembly. It serves as a road map to help the state respond to the looming demand for long-term care services driven by demographic trends, including the aging of the population, and soaring Medicaid expenditures.

Legislators consulted with the Connecticut Commission on Aging and the state's Long-Term Care Advisory Council and Long-Term Care Planning Committee in selecting UConn Health Center to conduct the assessment.

The resident survey was mailed to 15,500 people, including 5,250 older adults born before 1946, 5,250 baby boomers born between 1946 and 1964 and 5,000 people with disabilities. The survey was also posted on several websites and made available to all residents who wished to participate. A separate survey was sent to 1,211 long-term care providers and service organizations in both the public and private sectors.

Results were presented to the General Assembly, members of the public and advocacy groups at a Jan. 16 briefing in the Legislative Office Building.

80% Want to Stay at Home

The survey found that almost 80 percent of Connecticut residents want to remain in their own homes and communities when they require long-term care, using home health or homemaker services.

But, says Robison, "There's a disconnect between what people say they want in terms of long-term care—independence, choice and control and to stay in their own homes and communities—and how they plan to pay for that independence.

"Many people think Medicare or traditional private health insurance will pay for these services and that's not the case," she says.

The federal Medicare program provides health care coverage for people 65 years of age and older and those under 65 with certain disabilities. It does not cover most long-term care services, including nursing home costs.

"Our assessment found that people of all ages have very little, if anything, set aside to pay for long-term care even though it can cost a person \$109,000 a year for nursing home care," Robison said.

Medicaid, the jointly funded state-federal program, is the primary payer of long-term care services in the United States. It covers people who are poor or have disabilities and those who have "spent down" their assets due to the high costs of long-term care and in doing so have become nearly impoverished.

Nationally, 10 to 15 million Americans currently need long-term care. Government estimates suggest the number needing paid long-term care services could nearly double to 27 million by 2050.

The UConn Health Center researchers say the same pattern holds true for Connecticut. More than 188,000 state residents 40 years of age and older currently require long-term care and the number is expected to jump nearly 30 percent, to more than 240,000, by 2030. Demand for services will be far higher among persons 60 years of age and older.

Connecticut's \$2.2 Billion Medicaid Tab

Robison says Connecticut's Medicaid program spends more than \$2.2 billion a year on long-term care services, the second largest expenditure in the state budget after education.

Sixty-eight percent of the Medicaid long-term care budget is spent on institutional care, with the remainder funding home and community-based care. According to Connecticut's 2007 Long-Term Care Plan, the fraction of overall state health care spending going to nursing homes—15 percent—is the largest in the nation.

The survey found that more than 40 percent of respondents say they can pay nothing for long-term care while 25 percent can pay less than \$10,000 a year. Fewer than 20 percent say they can pay \$25,000 or more a year.

Four out of ten baby boomers—who began turning 60 years old in 2006 and who number one million in Connecticut—report they can pay nothing for long-term care. Fifty percent of respondents 85 years and older say they can pay nothing.

Many respondents recognize that home modifications such as a wheelchair ramp or a full first floor bathroom would enable them to stay in their home and age in place.

The UConn researchers emphasize, however, that “Medicaid...does not support the vast majority of people in their homes.”

'Rebalancing' the Long-Term Care System

Nationally, increasing attention is being given to expanding consumer choice and self-direction in long-term care, according to the UConn report.

Efforts to “rebalance” the system—to change the focus and funding priorities from institutional to home and community-based care—are driven by disability rights advocates, the growing strength of advocacy groups representing both older adults and persons with disabilities working together, self-advocacy and the aging of consumer-oriented baby boomers.

Based on data from the state Department of Social Services, the UConn team reports that the average monthly Medicaid expenditure for home and community-based long-term care is substantially less than institutional care across all age groups.

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The cost difference to the state under Medicaid between home and community-based care and institutional care is most dramatic for people from birth up to age 21--\$1,754 per month compared to \$27,247. For persons 65 years of age and older, the comparison is \$1,352 to \$5,112. For persons 22 to 64, the difference is \$5,551 per month compared to \$7,712.

“These findings strongly reinforce the fact that we need to rebalance the long-term care system to give older adults and people with disabilities greater independence and choice while using state and federal funds efficiently,” said Julia Evans Starr, executive director of the Connecticut Commission on Aging.

“Certainly there are challenges—the workforce shortage crisis is one—but we’re convinced that by working together we can provide thousands more people with home and community-based options for care sooner rather than later,” she said.

In addition to the resident and provider surveys, researchers reviewed Connecticut’s existing array of services and long-term care system rebalancing efforts.

They worked with Drs. Robert Kane and Rosalie Kane of the University of Minnesota, national long-term care experts, who compared Connecticut’s rebalancing efforts to progress in eight other states.

While some important progress has been made, UConn says, Connecticut ranks in the middle among all states for rebalancing expenditures.

In fiscal year 2005, Connecticut ranked 26th, with only about a third of its total Medicaid long-term care expenditures spent on community -based services. Oregon, the top-ranked state, spent 70 percent of its Medicaid long-term care dollars on community-based services.

“We need to recognize that this is not an ‘older person’ issue or a ‘person with disabilities’ issue; those are artificial silos within state agencies and programs that fragment the system and impede progress by dividing limited funds and resources. The needs recognize no age or disability boundary,” Evans Starr said.

The Long-Term Care Needs Assessment report, executive summary and recommendations are available on the Connecticut Commission on Aging website at www.cga.ct.gov/coa.

UConn Needs Assessment Recommendations to General Assembly

The following are highlights of the major recommendations contained in the Long-Term Care Needs Assessment presented to the General Assembly:

1. Create a single point of entry or “no wrong door” long-term care information and referral program across all ages and disabilities.
2. Adopt major policy and financing efforts to provide a broader range of community-based services for long-term care.
3. Foster flexibility in home-care delivery.
4. Address the scope and quality of institutional care.

5. Provide true consumer choice and self-direction to all long-term care users.
6. Simplify Connecticut's Medicaid structure by adding essential community-based services and striving for universal coverage across ages and disabilities.
7. Create greater integration of state-level functions to best meet residents' long-term care needs through a consolidated, efficient all-ages human services approach that maximizes the impact of Medicaid and Older Americans Act funds rather than dividing them.
8. Address the public's education and information needs.
9. Increase the availability of readily accessible, affordable transportation.
10. Address the long-term care needs of persons with mental health disabilities.
11. Address access and reimbursement for key Medicaid services.
12. Expand and improve vocational rehabilitation for persons with disabilities.
13. Address the long-term care workforce shortage.
14. Support informal caregivers.
15. Expand efforts to build data capacity and system integration to provide better management and client service.



Additional Long-Term Care Needs Assessment Information

Definition of Long-Term Care: “Long-term care refers to a broad set of paid and unpaid services for persons who need assistance due to chronic illness or mental or physical disability. Long-term care consists largely of personal assistance with the routine tasks of life as well as additional activities necessary for living independently. Unlike medical care, the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning in the course of everyday activities and to contribute to independent living.” *Connecticut Long-Term Care Plan. A Report to the General Assembly. January 2007.*

- By 2050, up to 27 million Americans may need care by formal caregivers. More than 188,000 Connecticut residents 40 years of age and older currently require long-term care. The number is expected to jump by 28 percent to over 240,000 by 2030.
- The number of Connecticut residents aged 75 and over is expected to increase by 54 percent within 24 years. In comparison, the state’s overall population is expected to increase by only 5 percent.
- Although Medicare actually pays very little for either long-term nursing home or home and community-based care, 38 percent of survey respondents think Medicare will pay for their long-term care. Almost half of those over age 60 think Medicare will pay.
- Medicaid, the anticipated long-term care funding source for more than one-fifth of the survey respondents, does not support most people in their homes.
- A long-term care workforce crisis looms as younger people leave Connecticut and the aging population soars. The problem is exacerbated by the negative image of many long-term care occupations due to low wages, poor benefits and difficult working conditions.
- Seventeen percent of all Long-Term Care Needs Assessment respondents say they provide unpaid care for a relative or friend in Connecticut. Across the nation, 44 million “informal” caregivers provide services with an estimated annual economic value of more than \$306 billion. This figure far exceeds public expenditures for formal home health care (\$43 billion) and nursing home care (\$115 billion).
- Demand for nursing home services in Connecticut is expected to rise by 43 percent by 2030, with a 67 percent increase in the number of persons 65 to 74 needing this care. The increase in demand can be reduced if the state’s Long-Term Care Plan goals for “rebalancing” institutional and community-based services are met. However, even if the goals for rebalancing are met, the need for nursing home care is still expected to grow by 25 percent.

- In fiscal year 2006--for the first time in Connecticut--more individuals (51 per cent) received Medicaid long-term care services in the community than in institutions. This is a significant milestone in the state's 2004 Long-Term Care Plan. However, 68 percent of the more than \$2 billion state Medicaid long-term care budget is spent on institutional care while 32 percent is spent on care in the community.
- Connecticut residents say that independence, choice and control are key long-term care needs when using any type of long-term care services.
- Connecticut provides publicly financed long-term care services and supports through a fractured governance structure consisting of a vast array of departments and programs that often operate in "silos" serving narrowly defined segments of the population. This organizational complexity poses significant challenges for both consumers and providers of long-term care services.
- The most progressive states in terms of long-term care "rebalancing" have restructured their state governments by consolidating most or all of their long-term care programs into a single agency within an umbrella organization, creating an efficient all-ages human services approach specifically linking long-term care and Medicaid.
- Nearly 80 percent of survey respondents wish to remain in their own homes, using health or homemaker services to meet long-term care needs. Almost as many recognize that home modifications, such as a wheelchair ramp or modified full first-floor bathroom, would let them stay at home and age there.
- Most respondents report that home maintenance, handyman service, lawn care and snow removal are essential for independence as they grow older. Other important needs include homemaker services, transportation and home health or personal care.
- The overall lack of affordable and safe housing is a concern for both providers of long-term care and residents wishing to remain in their communities. Survey respondents also mention the need to control rent increases, the need for rental assistance, financial aid or subsidized housing.
- Less than 30 percent of survey respondents believe they will live in a nursing home in the future. Most say living with an adult child is just slightly more expected than moving to a nursing home.
- More than one-third (38 percent) of survey respondents who need paid long-term care services say they are unable to get all the community-based services they need. The inability to afford services and lack of knowledge about available services top the list of barriers to getting needed care.
- Many providers of paid long-term care services recognize they can't meet all the needs of people who have impairments or disabilities that make community living difficult. They say the major missing services include transportation, supportive housing or homecare and health care such as psychiatric and dental services.
- More than 40 percent of providers say the regulatory environment affects their ability to provide services to clients. They cite issues with state and federal funding and reimbursement rates, regulations, limited services, documentation, interpretation and response time.