Testimony before the New York State Assembly and Senate Health Committees

by

Henry Moss, PhD
Board Member, Physicians for a National Health Program, NY Metro Chapter

May 28, 2019

Long-term Care and the New York Health Act

On February 11th, the 2019 version of the New York Health Act was introduced into the State Senate. It included, for the first time, a benefit covering long-term care, also known as Long-term Services and Supports. These services and supports will be available to all New York residents, regardless of income or immigration status, and without premiums or cost-sharing. Services will be at least as comprehensive as in the current Medicaid state plan and waiver programs, which are among the most comprehensive in the nation, and will prioritize care at home and in the community, rather than in nursing homes and other institutions. In addition, the legislation requires that advocates for disability rights and older adults be included on the New York Health Board of Trustees and on Regional Advisory Committees.

What will this mean for New Yorkers?

For millions of working and middle-class older adults and those approaching retirement who are not poor enough to qualify for Medicaid or rich enough to afford long-term care insurance or pay cash for a personal care aide or nursing home, it means knowing that personal care assistance will be there should disability, chronic illness, cognitive impairment, or frailty make it difficult to carry out the basic activities of daily living. These include activities like bathing, toileting, dressing, feeding, or moving about, along with essentials such as shopping, cooking, housekeeping, and financial management.

But what about Medicare? There is a persistent misunderstanding of how public programs relate to long-term care. Nearly all public funding for long-term services and supports in New York comes from the Medicaid program, only available to those who are very poor or who impoverish themselves to qualify. Medicare does not cover long-term services and supports, except in limited circumstances.

For younger adults with disabilities, enacting the New York Health Act will mean no longer having to forgo higher education, good careers, or raises and promotions, in order to remain poor enough to qualify for publicly-financed long-term care.

For family caregivers, it means no longer having to quit a job, forgo a job, or reduce work hours in order to provide unpaid care to a loved one. Of course, providing such care for a younger adult can last a lifetime. It also means getting relief from the extreme emotional burden of caring for those with dementia and other difficult-to-manage behavioral impairments. Over 2 million unpaid family caregivers provide over 2 billion hours of unpaid care in New York State every year. Half of those hours, one billion, are devoted to those suffering from dementia.

For personal care aides and home attendants, it means gaining recognition for the vital role they play and becoming valued members of health care teams. Most care workers today suffer from poor pay, poor working conditions, and lack of opportunities for advancement, and they suffer among the highest rates of injury, burnout, and turnover of any field of employment. To meet its statutory obligation to provide all necessary care to all state residents, the New York Health Board will work to change these conditions. This is imperative in the light of current shortages of such workers, especially in rural communities upstate, and the prospect of worsening shortages across the state as the huge boomer generation becomes the oldest old over the next 20 years. We already know that the number of available family caregivers will decline over this same period, a result of what some call the post-boomer birth dearth.

It is one of the sad ironies of our current system that as we extend lives with better diagnostics, medications, and surgery, we will see many more entering their 80s over the coming decades. Yet large numbers of these "oldest old" will

have disabilities, due largely to the lifetime effects of obesity, including high blood pressure, high cholesterol, systemic inflammation, and metabolic disorders like diabetes. Of particular concern is the impact of high blood pressure and inflammation on the brain, portending an increase in the incidence of Alzheimer's and other dementias.

We will need, therefore, to hire and train an army of personal care aides to deal with such an eventuality. They will need to be well-paid, have improved working conditions, and be treated as valuable paraprofessionals.

The inclusion of long-term care in the New York Health Act also addresses a number of longstanding social inequities.

The first is the persistent undervaluing of caregiving, a major feminist issue. 75% of unpaid family caregivers are women and they account for an even higher percentage of care hours. They also do the most difficult care work, and they do it for free! With women having entered the work force in huge numbers over the last 40 years, to pursue a favored career or maintain a middle-class lifestyle for their families, they now find themselves forced to forgo or quit employment, or reduce hours, usually during peak earning years, to care for loved ones. This is a serious hardship and a serious injustice.

And 90% of paid personal care workers and home attendants are also women, mostly immigrants and women of color, many with families and caregiving responsibilities of their own. They are hardworking and dedicated but it took a Supreme Court decision in 2015 to end classifying these workers as the equivalent of babysitters, allowing them to qualify for overtime pay and other benefits. But they continue to be exploited and suffer poor pay and working conditions.

The second inequity lies deep in our current long-term care system. It is sometimes called the "medical model" and is part of why nursing homes and mental institutions are so dehumanizing and depressing. The original Medicaid mandate, which remains in force today, only guarantees a disabled person a semi-private room in a nursing home or other long-term care institution. We are well aware that such institutions are chronically under-resourced and unacceptably

high staff to patient ratios. Unless one can afford an elite private facility, patients must endure fixed meal schedules, lack of access to favored entertainment and cultural activities, a regimented environment, and intense boredom as they sit in wheelchairs across from the nurses' station waiting for their next meal.

After living in their own home for their entire life, they are thrown into a fixed, sanitized, and depressing environment.

Although state waiver programs have begun to reduce the role of institutions, the medical model for long-term care must end and, by prioritizing home and community care, the New York Health Act is a great step forward. We know that quality person-centered care at home gives patients control over their lives with positive health consequences. Poor personal care, insufficient hours of care, living alone, or institutionalization leads to depression and anxiety disorders and worse physical health outcomes. We have all witnessed the rapid deterioration of mental and physical health in those entering even good quality nursing homes.

The third inequity relates to cost. Even many supporters of universal health care legislation worry about the cost of adding long-term care. It took intense lobbying by advocates for people with disabilities to force Senator Sanders to finally add long-term care to his Medicare for All legislation last month. The omission unfortunately furthered the idea that personal care is not really health care and perpetuated the inequities just described. We can spend thousands of dollars treating a retired worker for congestive heart failure or cancer, but offer nothing to help her prepare and eat breakfast at 6am.

Yet a recent report by the well-respected RAND Corporation showed that long-term care can be included in the New York Health Act with only a modest and reasonable increase in cost. This is largely because family members are actually willing to provide care to loved ones. When Scotland introduced a universal, free long-term care system in 1998, they set aside a large reserve of funds in anticipation of family members dropping most care. But the reserve fund was barely used. They discovered that family members were happy to provide care for loved ones. They only wanted to be able to pursue employment or be relieved of some of the more burdensome care.

In addition, as we move away from institutions toward home and community care, the per capita cost of long-term care is expected to decline. Either way, though, supporting the disabled among us and their caregivers is just the right thing to do, regardless of cost.

We all know someone who is receiving long-term care, giving care or who will soon be giving or receiving care. We also know how this impacts the health and well-being of both caregiver and care receiver. We understand the physical, emotional, and economic burden it creates for families and communities. With the inclusion of long-term care in the New York Health Act, we are not only addressing the concerns of older adults, younger adults with disabilities, family caregivers, and home care workers, but addressing the concerns of all New Yorkers.

Attachments

- Long-term Care and the New York Health Act: Frequently Asked Questions
- How Medicare recipients will benefit from the New York Health Act

For comments and correspondence:

Henry Moss PhD
hmoss011@gmail.com

Attachment 1

Long-term Care and the New York Health Act

Frequently Asked Questions

The New York Health Act includes long-term care as a benefit. This will affect the lives of millions of older and younger adults with disabilities, cognitive impairment, and chronic illness, and their caregivers. It is important to understand what the new benefit involves.

What is long-term care?

Long-term care, also known as long-terms services and supports (LTSS), is the personal custodial care we need when chronic illness, physical disability, cognitive impairment, mental illness, or frailty makes us unable to carry out our normal activities of daily living (ADLs). *Basic ADLs* include toileting, grooming, dressing, bathing, feeding, transfer (e.g., into and out of bed), and moving about. *Instrumental ADLs (*IADLs*)* include shopping, banking/personal finance, cooking, travel, and general housekeeping.

This definition includes the monitoring and "cueing" provided to those who suffer from dementia or other conditions that put themselves or others at risk, regardless of their ability to perform ADLs. LTSS may also include assistive technology, home modifications, transportation, and some social support services currently included in New York Medicaid programs.

How is LTSS delivered?

Care is provided in nursing homes, mental health institutions, and intermediate care facilities including those serving individuals with intellectual or developmental disabilities. It is also increasingly provided by personal care assistants, home attendants, and domestic workers in private homes and in settings such as assisted living facilities, senior residences, group homes, and adult day care centers. Depending on need, personal care in such environments can range from a few hours per week to round-the-clock care.

Long-term care is also delivered by unpaid caregivers, family members and friends. The AARP Public Policy Institute estimates that, in 2013, 2.5 million family caregivers In New York provided 2.4 billion hours of unpaid care that year, estimated at $31 billion in economic value based on the average wage of a home care worker. Nearly half of the care was directed to older adults with Alzheimer's and other dementias.

Who currently pays for LTSS?

Most paid LTSS (60%) in New York is delivered through the Medicaid program and is only available to the poor or to those who impoverish themselves to qualify. A small amount (5%) is paid for through Medicare. The remainder (35%) is paid out of pocket or through private

sources and long-term care insurance. Only 8-10% of New Yorkers have such insurance, due largely to its high cost and unreliability.

Unpaid family caregivers often pay indirectly by leaving jobs or reducing working hours in order to care for a loved one. They also suffer high levels of mental and physical disorders when the care is especially burdensome.

What kind of LTSS benefit will be available through the New York Health Act?

LTSS will be available for all New York State residents who are determined to need help with activities of daily living. This means extending the current New York Medicaid LTSS plan, among the most comprehensive in the nation, to all New Yorkers. New York State provides a range of institutional and home and community-based options. These include the Consumer-Directed Personal Assistance Program (CDPAP) which allows a capable client to hire, train, direct, and fire personal care aides that are paid by the state through a fiscal intermediary.

The legislation makes clear that there will be a preference for home and community-based care. This aligns with the U.S. Supreme Court's 1999 Olmstead decision requiring that care be offered in the least restrictive form possible to be compliant with the Americans with Disabilities Act.

Will the long-term care benefit include cost-sharing?

There will be no premiums, deductibles, co-pays, or narrow networks associated with the new benefit. However, NY Health is paying primarily for the personal care service (and related technology, home modifications, and social services). As with the current Medicaid program, the cost of room and board at an institution, assisted living facility, senior residence, or other facility is not covered. However, for those living at home and needing help with housing, food service, transportation, counseling, day programs, and other social services not currently included in the Medicaid program, there are other New York programs that will continue to be available.

What will the new benefit cost the state and how will it impact NY Health taxes?

The 2018 RAND Corporation economic analysis of the New York Health Act concluded that long-term care would add roughly $18 billion to total health care spending in the state, an increase of only 6.4%. The $18 billion represents an expected shift of about half of unpaid family care to paid formal care. An additional $11 billion will be needed to cover current out-of-pocket spending, including spending for long-term care insurance. The new taxes will need to cover this $29 billion in a launch year of 2022, a 22% increase in New York health taxes.

The additional tax pays for a valuable long-term care benefit which will finally make necessary care available to the vast majority of working and middle-class New Yorkers.

Attachment 2

How Medicare Recipients Will Benefit from the New York Health Act

Today, Medicare recipients spend an average of $6,100 -- 22% of their income – on health care. Under the New York Health Act, New Yorkers will keep their Medicare coverage but will gain valuable new benefits. Out-of-pocket costs will be eliminated, ending any financial worries when seeking health care. Any New York Health taxes they pay will often be far less than they are now paying to insurance companies and in out-of-pocket costs, and they will receive the health care they need when they need it.

Health Care Service	Medicare	New York Health
Hospital care	Deductibles and Copays	$0
Physician care	Part B premium, deductibles, copays	$0
Prescription drugs	Part D premiums, deductibles, copays, coinsurance	$0
Dental, hearing, vision	Limited coverage only by certain Medicare Advantage plans usually with added costs and restricted provider networks	$0
Long-term care	Not covered	Covered at no cost

How Medicare Recipients Will Benefit from the New York Health Act

- New Yorkers under New York Health will retain their Medicare coverage while enjoying added benefits including vision, dental, hearing, full drug coverage, full mental health coverage, and long-term personal care in all settings. Medicare Advantage plans and Medigap supplemental insurance will no longer be necessary.
- Long-term care coverage will emphasize home- and community-based care, with institutional care available, if needed.
- There will be no cost-sharing; no deductibles, copays, co-insurance, or pharmacy donut holes. Medicare Part B and D premiums will be covered by the New York Health plan.
- Medicare cards can be used when out-of-state. New York Health will cover any deductibles and co-pays if you need medical care while traveling.
- Instead of cost-sharing, Medicare-eligible New Yorkers will help finance the program through progressive taxes on payroll income (if they are working) and taxable non-payroll (investment) income, based on ability to pay. Since Social Security income is not subject to state taxes in New York, the vast majority of Medicare beneficiaries will pay far less than they currently pay in premiums and cost-sharing, if they pay any New York Health tax at all.
- The federal and state governments will continue to provide New York with its current share of Medicare, Medicaid, and other public health funds.
- Billions will be saved by eliminating the wasteful overhead expenses and profits of commercial insurance and by negotiating lower prices for drugs and medical devices. Health care providers will no longer waste time dealing with insurance companies and can spend more time taking care of our health.