

**Testimony before the New York State Assembly and Senate Health Committees  
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by

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**Long-term Care and the New York Health Act**

On February 11, 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.<sup>1</sup> About half of those hours are devoted to those suffering from dementia.<sup>2</sup>

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.

## Caregiving inequities

The inclusion of long-term care in the New York Health Act also addresses 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 have 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.

### **Estimating the cost of long-term care in New York**

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 main worry is replacing unpaid care given by family members and friends with paid care, either paying family members or providing a paid personal care aide. This is sometimes called a “welcome mat” or “woodwork” effect reflecting the hidden nature of the delivery of care by unpaid caregivers

The AARP Public Policy Institute estimates that 2.4 billion hours of unpaid care were provided by family and friends to disabled New York State residents over the age of 18 in 2014.<sup>3</sup> If each hour were paid at the prevailing wage of an agency personal care aide, about \$13 per hour on

average, the value of this care would be \$31 billion per year.<sup>4</sup> The AARP estimate is based primarily on surveys of caregivers. For the reasons explained below, only about \$18 billion will actually be needed.

### **Medicaid rules**

The new benefit will effectively expand the Medicaid Home and Community-based Services (HCBS) personal care program to the entire population, but Medicaid has certain requirements. When Medicaid assesses need, it considers the availability of informal caregiving and will not approve the use of a paid personal care aide during hours when a healthy family member would be present. This limits care hours generally, but especially in situations when the client is living with the caregiver. About 35% of clients have this arrangement.<sup>5</sup> A paid aide would typically be used when a family member needs to be out of the home, at work, for example, or school. In addition, disabled adults living with healthy spouses would normally not receive authorization for formal care, and the Consumer-directed Personal Assistance Program (CDPAP) does not allow spouses to be paid as caregivers.<sup>6</sup> Although spouses constitute only 1 of 10 caregivers, they provide the most extensive care, upwards of 40 hours weekly.<sup>7</sup>

### **Caregivers will continue to provide unpaid care**

Family caregivers generally have a positive attitude about caring for a loved one. Their concern relates primarily to the need to be in the work force, or at school, or to the demands of highly intensive care such as would be needed, for example, by an advanced stage dementia patient. Otherwise, studies have shown that when public financing of home care is made available, family caregivers do not stop providing care. Instead they often reduce just a portion of the care devoted to managing basic ADLs and switch to lower-intensity care and care that helps care recipients engage in cultural activities and maintain social connections with their families and communities.

A 1994 Brookings Institution review found that “most studies suggest that when disabled elderly receive paid home care, unpaid care does not change significantly.”<sup>8</sup> A study of 52 home and community care demonstration projects found that only four showed a reduction of family caregiving hours. Seven studies showed an increase, and 41 showed no statistically significant change.<sup>9</sup>

Scotland introduced a universal, free long-term care program in 1998, covering institutional care and home care with no financial eligibility restrictions. By 2002, it was fully up and running. They set aside a pool of funds they thought might be needed to address increased utilization, but the fund was largely unused. According to a 2005 study by the Joseph Rowntree Foundation, initial woodwork effects were minimal:

...the fear that free home care would mean a dramatic reduction in informal care by family and friends has not materialized. Nor has there been an explosion in the numbers of people receiving free personal care at home. Informal carers are continuing to put in

similar hours as before, but there has been a constructive switch in the way that care is provided from the more mundane and intrusive tasks (such as washing and dressing) to social interactions such as outings.<sup>10</sup>

Again, the use of formal caregiving was limited to relieving only part of the total caregiving hours needed. In some cases, care recipients and/or their families were simply reluctant to have a stranger join their household for any extended period of time.

### Limits to IADL care

When Medicaid approves hours of daily care for ADLs by an agency aide, it is expected that during these hours, the aide will provide some care involving instrumental activities of daily living (IADLs), including light housekeeping, cooking, and, where appropriate, assisting with shopping, banking, and necessary travel. If IADL care hours can be billed directly, as when an assisted living facility provides a weekly cleaning service, Medicaid limits reimbursement for such activities to 8 hours weekly.<sup>11</sup>

The NY Health program will be based initially on expanding Medicaid LTSS to all residents. Yet, Medicaid does not necessarily recognize all hours devoted to IADL care as necessary for keeping a client out of a nursing home. 60% of the care hours reported in the AARP surveys were devoted to IADLs, including tasks like spending a day or part of a day with the client at a family, community, or church event.<sup>12</sup> Such activities, while valuable in themselves, may not be considered essential and may not be eligible for Medicaid consideration.

### Supply constraints

Finally, while nursing home beds are generally available (and hospital beds can be used to accommodate a short wait), there is a significant and growing shortage of home care workers in the U.S. and in New York. The shortage is due, in part, to the 1999 Olmstead decision of the Supreme Court. The Court ruled that the Americans with Disabilities Act required that long-term care be offered in the least restrictive setting possible.<sup>13</sup> It is also due to increasing demand, which will continue to grow as the population ages. In 2014, the Bureau of Labor Statistics estimated that over one million home health and personal care workers would need to be hired nationally by 2022.<sup>14</sup> In New York, this situation is already expressing itself in serious shortages of home care workers in upstate New York, particularly in rural counties where transportation and weather issues place additional burdens on care workers.<sup>15</sup>

New York is addressing the upstate crisis with emergency funding and the longer-term problem is being addressed by increasing the state minimum wage and enforcing new federal requirements concerning overtime pay for home care workers. This is an uphill battle, however, because home care agencies, whose major expense is care worker compensation, are seeing their financial situation as increasingly precarious given very low Medicaid reimbursement rates. As a result, some are attempting to skirt the new rules by manipulating worker schedules to avoid overtime pay and benefits.

Many upstate clients currently authorized for home care wait for months to be assigned an aide. The problem is expressing itself in New York City, as well, through a lowering of standards for hiring. Aides with significant language and literacy deficits, and limited cultural competency, are being deployed into homes. This is reflected in increasing consumer complaints, aide-client incompatibility, and turnover.<sup>16</sup>

While this is not a good situation, it will limit the cost of extending home care services to all New York residents as the problem gets resolved. Informal caregivers, reluctant to place loved ones in nursing homes, will remain in place while clients wait to access acceptable services. This will further limit woodwork effects as the state legislature and NY Health work to increase the supply of care workers.

### Financing long-term care

Given the above constraints, the RAND Corporation analysis of the New York Health Act estimated that only about 50% of currently unpaid care would switch to paid care, 90% to home and community-based care and only 10% to the more expensive institutional care. This will amount to about \$18 billion in 2022.<sup>17</sup> A 2016 Urban Institute report on Medicare for All had similar modest increases.<sup>18</sup>

Using the RAND figures, we estimate that the new legislation would need to raise \$29 billion in new revenue in 2022 to cover this new paid care, the \$18 billion, plus the \$11 billion currently paid by private sources, long-term care insurance, and out of pocket<sup>19</sup>. Using a reasonable progressive payroll tax structure, the employee share of the payroll tax would go from \$566 per year to \$690 for someone earning \$50,000, \$124 per year/\$10 per month more, a pretty good deal for long-term care insurance considering how expensive it is in the private market. The number would rise to \$2455 from \$2013, or \$442 per year more, for someone earning \$100,000<sup>20</sup>.

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.

And there would be important implications for the private economy, bolstering the workforce as the population ages, reducing the burden being placed on younger workers to finance retirees, and increasing spending in local businesses.

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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.

## Attachment

- Long-term Care and the New York Health Act: Frequently Asked Questions

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## **Notes**

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## 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-term 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 cost of the new benefit will be modest. The 2018 RAND Corporation analysis of the New York Health Act concluded that long-term care would add \$18 billion to total health care spending in the state, an increase of about 5%. 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 spending by private sources. The additional tax needed to cover the added expense will be about \$120 per year for an individual earning \$50,000, according to one estimate, rising to \$440 for someone earning \$100,000 annually. 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.