Testimony submitted to the Joint Legislative Budget Hearing

In support of the *New York Caring Majority* budget recommendations

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February 25, 2021

Long-term care, home care workers, and the 2022 budget

My name is Henry Moss and I live in Senator Biaggi's district. I'm writing to support the New York Caring Majority efforts to increase budget support for disabled older and younger adults and the workers who care for them. This articulates with the effort I helped lead to have long-term personal care included in the New York Health Act, single-payer legislation that has passed the Assembly multiple times and is near passage in the Senate

Much needs to be done to improve and expand long-term care as the population ages, worker shortages worsen, and the emotional and economic burden on family caregivers grows. Two recommendations are especially important for the joint session discussion.

First, the legislature should reverse the recent cuts to the Medicaid personal care program caused by tightened medical and financial eligibility rules and the global Medicaid cap. These cuts make no sense. They are causing harm and any savings will be reduced by the cost of treating those who suffer the falls, infections, nutritional deficits, and other adverse effects that result from failing to provide assistance with basics like shopping, cooking, and housecleaning, among other activities of daily living. I've provided details about these negative impacts in the appendix.

Savings will be further reduced by the economic impact of family caregivers in their peak earning years leaving the work force or reducing work hours to provide this needed care.

Secondly, the delivery of care will not be possible if we don't recruit and train more home care workers. Home care is a difficult job involving high levels of burnout, injury, and turnover. We must treat home care workers as respected paraprofessionals and a valued part of the care team. Most importantly, the conditions of employment must be improved. These hard-working and dedicated aides need stable schedules, a career path, and union-level pay and benefits. This means making the *FairPay4HomeCare* legislation as part of the budget process. The legislation will be introduced by Senator May and Assemblyman Gottfried in the next few weeks

How cuts to Medicaid personal care services in New York will harm disabled older and younger adults.

A report submitted in conjunction with testimony in support of the New York Caring Majority's budget recommendations at the February 25, 2021 Joint Legislative Budget hearing

by Henry Moss, PhD

Thousands of Medicaid-eligible disabled New Yorkers are not in need of a nursing facility or other institution but still need some assistance with daily activities in order to live independently at home or in a community setting. New York State has led the nation in making such services available through a generous and comprehensive Personal Care Services (PCS) program included in its Medicaid state plan. Anyone with a need for a personal care assistant (PCA), whether for a few hours a week or 24/7, and who can be safely cared for at home, is eligible for the care. Physicians certify the need and functional assessments are conducted to establish the scope, hours, and timing of care. Nurses then monitor the care plan, supervise the PCAs, and take care of any ongoing or emergent medical issues.

The Cuomo administration has included a significant cut to this exemplary program in the 2020 state budget that aims to balance the budget, in part, by addressing unanticipated growth in Medicaid spending. It appears the administration hopes to save over $500 million through two changes to the PCS program:

- Restrict medical-eligibility to only those with a nursing home level of need (assistance with three or more basic activities of daily living), starting in October 2020.
- Centralize the assessment process in order to curb what the state contends have often been overly generous care plans developed at the local level.

The Governor claims that the cuts will not compromise the health or safety of patients suggesting that some services offered in the PCS program are unnecessary and wasteful. What he is really saying, however, is that the program is too generous, going beyond services offered in other states. His supporters point out that spending on personal assistance programs, including the variant known as the Consumer-directed Personal Assistance Program (CDPAP), widely used by younger disabled adults to assure control of their care, has doubled over the last four years. They also note that per capita Medicaid personal care spending has been consistently five or six times greater than the national average with New York accounting for as much as 40% of national spending on these services.

Budget watchdogs have frequently pointed to the generous PCS program as a potential source of savings. In 2006, the Citizens Budget Commission proposed significant cuts that, they claimed at the time, would save over $1 billion and yet still leave New York's program as one of the most generous in the nation. Here's how they put it[1]:

New York's program of personal care for the elderly and disabled living at home pays for more hours of home attendant services for tasks such as housekeeping and shopping than is authorized in any other

state. Bringing use of personal care services more in line with national norms would save about $1.5 billion annually. This assumes that the average number of hours of personal care authorized for clients can be reduced from the current average to a figure still 50 percent above the national average.

It is not surprising, then, that personal care services would come under attack. Given the size of the projected savings, this means that many thousands of New Yorkers will not have access to services recommended by their health care providers.

New Yorkers are being penalized for having a generous program and being a leader among the states in providing competent care for the most vulnerable among us. The care provided is not excessive. It is well known that the single greatest and most persistent complaint about long-term care in other states concerns inadequate hours of care for disabled adults living at home and in the community.

The changes being forced by the 2020 budget will severely weaken the PCS program and leave many disabled adults in unsafe and unhealthy conditions.

Medical eligibility changes

The current system for establishing medical eligibility for Medicaid home and community-based services (HCBS) in New York works as follows:

- A physician determines that a patient needs care for a disabling condition that will exceed 120 days duration and that the patient is otherwise medically stable.
- A medical professional, usually a nurse, proposes a plan of care establishing the type of care needed and the timing and hours of care. This involves the following inputs:
    - The physician's report
    - An objective assessment of functional limitation (New York uses the Uniform Assessment System)
    - Interviews with the patient and family members.
    - A determination that the patient or a friend or relative is able to direct the work of the PCA
- The care plan is approved by all parties and then by the local Medicaid office.
- An aide is secured through a licensed agency, or through the Consumer-directed Personal Assistance Program (CDPAP).
- A nurse is assigned to the patient to manage medications, vital signs, and any ongoing medical needs, and to ensure the effectiveness of the aide and the health and safety of the patient. This involves regular visits.
- The plan is evaluated on a regular basis to determine if any changes are needed.

The New York PCS program exists despite the fact that Medicaid law requires only that someone in need of extensive help with activities of daily living be offered a bed in a semi-private room in a nursing facility or other long-term care institution. Over time, and in response to public pressure, the ADA, and the 1999 Olmstead Supreme Court decision requiring

states to offer care in the least restrictive setting possible, the law was amended to allow states to offer home and community-based services (HCBS), if they so elected, through state plans and waiver programs.

As the move to HCBS progressed, however, there continued to be the assumption that recipients of HCBS would need to have a nursing facility level of need. Informally, this has been typically defined as limitation in the physical ability to perform two or three of the basic activities of daily living (ADLs) such as transfer (into and out of bed), movement (from one room to another), bathing, toileting, grooming, feeding, dressing, and administering medication.

New York and several other states have gone further, however, and developed state plans and waiver programs that expanded the level-of-need criteria. Dementia and other disabling mental and behavioral conditions were included, irrespective of the physical ability to perform ADLs. Patients needing only or mostly help with instrumental ADLs (IADLs), such as transport, shopping, banking, meal preparation, laundry, and general housekeeping, have also been included in the Medicaid program

Until the new budget, New York's personal care program had been defined as "services…essential to the maintenance of the patient's health and safety in his or her own home, ordered by the attending physician and based on an assessment of the patient's needs and of the appropriateness and cost-effectiveness of services." [18 NYCRR 505.14(a)].

Two levels of assistance are then defined in regulation as:

1. **HOUSEKEEPING or "Level 1"** - for those who because of disability need assistance with housekeeping, cleaning, meal preparation, grocery shopping, and laundry, but they do not need help with "personal care" tasks such as bathing or dressing. These services are limited by state law to eight hours per week. [18 NYCRR 505.14(a)(5)(as amended 12/2015)].
2. **PERSONAL CARE or "Level 2"** -- includes all of the Housekeeping (Level 1) tasks PLUS assistance with personal needs - bathing, dressing, grooming, toileting, walking, feeding, assisting with administering medications, preparing meals with special diets, and routine skin care. In amendments in December 2015, "turning and positioning" was specifically added as a task, as needed by bedbound individuals who cannot turn themselves, putting them at risk of bed sores.

With the budget law now requiring that eligible patients must be nursing-home eligible by "needing at least limited assistance with physical maneuvering with *more than two* activities of daily living" or having a qualifying dementia diagnosis, the implication is that the savings will come from those who do not have a nursing home level of need and who only or mostly need housekeeping and similar instrumental services.

Centralized assessment

These more restrictive eligibility requirements are reinforced in the budget law by the planned implementation of a tighter system of assessment and care planning, this time set to commence in October 2022. As stated in the bill (Section 365-a, subdivision 10):

The department of health shall establish or procure the services of an independent assessor or assessors no later than October 1, 2022, in a manner and schedule as determined by the commissioner of health, to take over from local departments of social services, Medicaid Managed Care providers, and Medicaid managed long term care plans performance of assessments and reassessments required for determining individuals' needs for personal care services, including as provided through the consumer directed personal assistance program, and other services or programs available pursuant to the state's medical assistance program as determined by such commissioner for the purpose of improving efficiency, quality, and reliability in assessment and to determine individuals' eligibility for Medicaid managed long term care plans.

According to the budget planning team, centralized assessment and planning will allow the state to better control costs. In particular, they can identify local physicians, nurses, and administrators who have been using more liberal interpretations of eligibility standards and care plan hours than those used elsewhere.

Such a centralized system, they claim, would both reinforce the new standards and create a more streamlined and less wasteful assessment and planning bureaucracy.

Impact on the health and safety of disabled New Yorkers

Who may be harmed by eliminating housekeeping and related services? It is difficult to give a precise answer to this question since the kinds of disabilities and levels of capability vary widely and differ across age groups. We can identify, however, some characteristics of those who need assistance, but who need help with fewer than three basic ADLs:

Frailty: Frailty has been identified as a clinically-recognizable syndrome characterized by a devolving cycle of muscle weakness, physical slowness, low physical activity, poor endurance, frequent exhaustion, and unintended weight loss. Sarcopenic frailty involves sedentary obese individuals whose muscle mass is being increasingly replaced by adipose tissue (fat) leading to the same cycle. Many frail individuals are still mobile and may only need assistance with one or two basic ADLs. Yet many of the tasks associated with housekeeping and other IADLs may be difficult or impossible to carry out.

Loss of dexterity: A number of conditions involve a loss of dexterity that compromises the ability to write, handle small items, use a knife or fork, or cook. It can also make using a phone or an ATM machine difficult. While some of these deficits can be improved with technology, many are functionally debilitating. Yet they may not qualify as requiring a nursing home level of care and fall short of the new standard. Rheumatoid arthritis, cerebral palsy, early-stage

Parkinson's disease, multiple sclerosis, essential tremor, and certain congenital neurological defects are just a few common conditions that can lead to loss of dexterity and the need for weekly help with certain instrumental tasks.

Blindness: Individuals suffering from blindness or poor eyesight may need assistance with shopping, cooking, bill-paying, and other basic tasks while not qualifying as needing a nursing home level of care.

Cognitive impairment: At any given time, there are those in the early stages of cognitive impairment who suffer confusion and disorientation that could lead to losing track of medical appointments, failing to take or purchase medications, or failing to carry out basic hygienic practices, such as showering. They may also fail to pay bills or carry out basic banking tasks. While a medical professional might recommend assistance with some of these tasks, such individuals may not be diagnosed with more advanced dementia or be at a nursing home level of care.

Those are just a few of many examples of cases where help is needed but below the level defined in the budget legislation. Among the potential consequences for patient health and safety are:

- *Falls*: It is well known that older adults are more susceptible to falls and far more likely to break a bone or need joint replacement surgery as a result. Serious falls can cause rapid mental and physical health deterioration leading to death. Frail older adults and those in the early stages of congestive heart failure and similar conditions may be able to get around without help with basic ADLs, but for whom even simple household tasks can be physically destabilizing and for whom shopping on their own would be precarious. Help with laundry, shopping, meal preparation and the like would serve to reduce the likelihood of falls.
- *Poor nutrition*: Without assistance with shopping and meal preparation, many frail or cognitively-impaired low-income older and younger adults may suffer nutritional deficits. In addition to experiencing deficits in healthy eating, there is the risk of consuming spoiled foods and other food-related safety concerns.
- *Poor sanitation*: Without weekly cleaning and laundry, disabled adults risk living in unsanitary conditions. This may include sleeping in soiled bedclothes and on soiled sheets and being exposed to mold, dust, and pathogens that can cause infections or exacerbate existing chronic conditions.

Conclusion

New York State has been a national leader in supporting the most vulnerable among us by allowing Medicaid-eligible and functionally-disabled older and younger adults to receive help with instrumental activities of daily life, including housekeeping, while living at home or in the community. This has allowed many thousands to leave or avoid institutions and live independently at home or in a community setting in compliance with the Supreme Court's

Olmstead decision and with the letter and spirit of the Americans with Disabilities Act. New York has also consistently supported popular programs like CDPAP that allow disabled younger adults to have control over the terms and conditions of care, care which can last a lifetime.

The budget cuts use the inadequacy of long-term care services in other states as an excuse. New York will be giving up its leadership role and risking the health and safety of vulnerable New Yorkers.

Note

1. Citizens Budget Commission of New York (2006) Medicaid in New York: Why New York's program is the most expensive in the nation and what to do about it. Available at http://cbcny.org/sites/default/files/reportsummary_medicaid_04202006.pdf