

PETITION TO SHIFT NEW YORK'S LONG-TERM CARE SYSTEM
FROM INSTITUTIONAL SETTINGS TO COMMUNITY-BASED HOUSING & SUPPORTS

January 19, 2021

Dear Governor Cuomo, Speaker Heastie and Majority Leader Cousins, and the Leadership and Members of the Assembly & Senate Committees on Aging, Health & Mental Hygiene:

We the undersigned, petition New York State government to take immediate steps to reorient our system of long-term care from congregate facilities to community-based services, supports, and housing. New York must realize the long-forgotten promise of the Americans with Disabilities Act and the Olmstead Integration Mandate. To meet basic safety, human dignity, and the choice of the vast majority of New Yorkers, community-based care must be the presumption, NOT the exception, in our long-term care system.

These steps are particularly urgent in response to the COVID-19 pandemic. As of October 26, 2020, 6,543 New Yorkers lost their lives to this pandemic while living in nursing facilities. We know that many more people have died in hospitals after contracting COVID-19 in nursing facilities, data that the New York State Department of Health has refused to provide.

While COVID-19 remains a continuing threat, it is only the latest evidence demonstrating nursing facilities' longstanding failure to control infection and provide basic health care to residents. Even before the pandemic, 82 percent of all nursing homes had infection prevention and control deficiencies cited in one or more years from 2013-2017, according to the U.S. Government Accountability Office. Forty-eight percent had such a deficiency cited in multiple years. Poor infection control was pervasive prior to COVID, both in New York State (where 54 percent of nursing homes reporting deaths from COVID had recent citations for infection-related violations) and in the out of state facilities where we send our children, parents, and other family, such as at the Wanaque facility in New Jersey, where 11 children died from the adenovirus in 2019 due to lapses in hand-washing and infection control, substandard care and poor oversight.

We send our family members to nursing facilities because the professionals tell us they need 24-hour care, and it is the only place to receive such services. However, the promise of safety, care and comfort in nursing facilities has not been met. Only a limited portion of services are skilled nursing. In fact, the average number of total care hours provided in New York's nursing facilities in the second quarter of 2020 was only 3.51 hours per day – **ranking 28th out of all 50 states** despite the high payment rates for nursing homes in NYS.¹ This level of care is less than what has been federally recommended in nursing facilities (at least 4.1 hours of total care, including .75 RN care – a level that can still be provided in the community).

Being able to choose where to live and how to receive needed supports, and by whom, should be recognized as a basic human right for all New Yorkers. Community-based housing with supports and services is the first choice of older adults who want to remain in their communities. Nursing services and personal care are provided safely, effectively and generally at lower cost in the community. The COVID-19 pandemic is a tragic wake-up call, and a test of our ability to re-imagine long-term care in ways that replace facilities with communities, nursing “homes” with real homes, and segregated approaches to care with assistance that permits full integration into the mainstream of community life.

We must face the truth that the nursing facility model has failed. It is time to work cooperatively toward a solution. We are calling upon you, the leaders of our great State, to take immediate

¹ Based on federal MDS data, available at <https://nursinghome411.org/staffing-q2-2020/>.

action, described below, as first steps to a better future for all New Yorkers.

In order to keep more people in their homes and communities we must:

1. Eliminate the institutional bias created by policies that create and increase barriers to community living.

A. Roll back the recently reinstated nursing facility carve-out from Medicaid Managed Long Term Care (MLTC). In a reversal of the State's 2013 Olmstead Plan, the carve-out was reinstated in 2019 for people who stay longer than 90 days in a nursing facility. This disenrollment greatly jeopardizes their transition to the community, and incentivizes MLTC plans to institutionalize individuals who are more disabled and have a greater need for services.

B. Roll back the new restrictions on access to consumer-directed personal assistance and agency-provided personal care services. These restrictions are intended to save Medicaid dollars, but will in fact drive people to leave their homes to receive more expensive and less humane facility care.

C. Roll back the newly required 30-month "lookback" review of finances in order to be eligible for Medicaid for community-based long term care services. This will cause delay of necessary services and force people into facilities while this lengthy process unfolds, and their mental and physical health will rapidly deteriorate.

2. Expand community-based services, supports and housing opportunities for New Yorkers who are disabled and/or are older adults.

A. New York State must address the personal care workforce crisis that has been created by decades of stagnant reimbursement and wages. Home care workers must receive livable, competitive wages (including benefits) that fully and appropriately acknowledge the vitally important, front line services they provide and helps to ensure their continuing, long-term availability.

B. Expand community-based care coordination for people who have mental illness and other chronic disabilities and who are enrolled in New York's Medicaid Health Homes program. Current care coordination services are stretched far too thin, leaving coordinators with unmanageable caseloads and thwarting their effectiveness. Too many people who need and could benefit from cost-effective community services do not receive them because they need assistance and encouragement to navigate the complexities of New York's fragmented support systems.

C. Behavioral health HCBS services must be expanded to serve individuals with histories of institutionalization in nursing homes, and eligibility should be expanded to individuals receiving Social Security Disability Insurance, not exclusively Supplemental Security Income.

D. Make rapid response support available for families experiencing a long-term care crisis. Families are often too overwhelmed to deal with all of the moving parts, (e.g. aggressive hospital discharge planners, arranging for aides, home modifications, and durable medical equipment) necessary for successfully returning a newly disabled person to their homes, resulting in unnecessary SNF placements. Such support would enable some to navigate this system successfully and return to their homes.

E. Expand “aging in place” housing models in integrated settings and the successful and cost-efficient supported housing model. For example, the Empire State Supportive Housing Initiative can fund properties to have certain numbers of accessible units and available staff. “Canopy of Neighbors” is another important community-based model that avoids institutionalization. The supported housing model should both be increased for those for whom it is currently used, such as people with psychiatric diagnoses and developmental disabilities, and made available to people with other cognitive disabilities, such as TBI and dementia. New York should promote policies that facilitate private investment in housing options that reduce costs and allow older adults to conserve their assets by avoiding institutional care.

F. Use targeted funding for housing and program development to establish rent subsidies for people who are older adults and/or physically disabled. Federal programs like the Housing Choice Voucher Program (“Section 8”) have been successful in keeping low income families affordably housed, but there are years-long waiting lists for these vouchers. People who have disabilities and/or are older often live on a modest fixed income from which they cannot afford to pay market rents, resulting in SNF placement. This is not only an affront to their dignity, but an unnecessary Medicaid expense that New York can ill afford.

G. Expand NYS housing subsidies under the Nursing Home Transition and Diversion and TBI Medicaid Waivers for long-stay residents transitioning from nursing homes and adult care facilities to housing in the community. These have successfully enabled thousands of New Yorkers to leave institutions and return to the community. Despite their success, recent changes have reduced the subsidy and made them much more difficult to obtain. This should be reversed immediately. Relatedly, expand the Special Income Standard for Housing Expenses After a Nursing Home or Adult Home Stay to include people accessing personal care or CDPAP through the Immediate Need procedure, not only those in MLTC plans.

H. Expand Open Doors Transitional Support. Open Doors transition specialists facilitate transitions to the community for nursing home residents, including locating housing and subsidies, accessing needed services, waivers, and supports, and providing education to develop independent living skills. The New York Association for Independent Living coordinates the Open Doors program. Many more specialists are needed, particularly in the New York City region.

I. Expand the Access To Home Program. This program provides assistance to eligible families to make accessibility modifications allowing them to remain in their homes rather than be displaced. Aging in place should always be the first option when faced with long term care challenges.

The time is now. New York State must take immediate steps to re-design our system of long-term care from congregate facilities to community-based services, supports, and housing.

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New York Association on Independent Living

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