CID-NY

Manhattan
841 Broadway
Suite 301
New York, NY 10003
212/674-2300 Tel
212/254-5953 Fax
646/350-2681 VP

Queens
80-02 Kew Gardens Rd
Suite 107
Kew Gardens, NY 11415
646/442-1520 Tel
718/886-0428 Fax
866/948-1064 VP

www.CIDNY.org

Center for Independence of the Disabled, NY

Testimony to the Senate Committee on Health, Senate Committee on Aging, Senate Committee on Investigations and Government Operations, Assembly Committee on Health, Assembly Standing Committee on Aging, Assembly Committee on Oversight, Analysis and Investigation

SUBJECT: Nursing homes, assisted living, home health care and COVID-19

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Testimony by:
Susan Dooha,
Executive Director
Center for Independence of the Disabled, NY

Thank you for the opportunity to testify today. We appreciate the opportunity to share with you our thoughts about nursing homes, assisted living, home health care and COVID-19 and our recommendations. Center for Independence of the Disabled, New York (CIDNY)[1] is a disability led non-profit organization founded in 1978. We base our comments on 42 years of work with people with disabilities of all ages in all settings.

The Supreme Court's Olmstead decision interpreting the Americans with Disabilities Act holds that people with disabilities have a right to live in the most integrated setting. Approximately half of our Center's staff assist individuals who wish to secure care at home, or another integrated setting so they may avoid nursing facility placement. These staff also help individuals leave nursing facilities for their own homes in the community.

There have been long standing unaddressed issues antecedent to the current pandemic that are affecting nursing facility and community residents with disabilities of all ages alike. These include:

Racial and Ethnic Disparities.

The pandemic has been disproportionately lethal among nursing home residents who are Black and Latinx. It is not a new observation that residents of color face worse outcomes due to structural racism, higher rates of chronic conditions characterized as placing someone at higher risk for COVID-19, lower staffing levels, higher numbers of deficiencies. The New York Times observed that nursing facilities serving primarily Black and Latinx residents had cases of COVID-19 at twice the rate of facilities primarily serving white residents.

- ***CIDNY supports a targeting of resources for testing, personal protective equipment, infection control expertise and staffing resources and a focus by health authorities on eradicating disparities in treatment and care in nursing facilities. Dashboards showing rates of infection and death in nursing facilities should publish racial/ethnic demographic information to increase transparency and focus attention on the impact of the pandemic in Black and Latinx communities. The New York State Prevention Agenda should focus***

[1] CIDNY's goal is to ensure full integration, independence and equal opportunity for all people with disabilities by removing barriers to full participation in the community. Our mission is to help people access the care and services people need to live independently in the community and we have focused on creating and strengthening community resources for care and assistance so that people with disabilities do not have to spend their lives segregated in institutions. We seek to protect and advance the rights of people with disabilities in all settings.

on racial/ethnic disparities in congregate facilities including nursing facilities and planning to eliminate conditions that result in a disproportionate impact in a pandemic based on race and ethnicity.

Infection control.

A May 2020 federal study found that 82 percent of nursing homes had deficiencies for an infection prevention and control standard during a five-year period prior to the coronavirus (COVID-19) pandemic, and that two-thirds of facilities had infection protection deficiencies in multiple years.

- ***CIDNY supported regulations proposed by the previous administration to require an infection preventionist at least half-time at nursing facilities.***

Safe Staffing.

Staffing levels at nursing facilities have long been an issue with staff turnover as high as 100%. This has been exacerbated during the pandemic by a high rate of staff illness, illness of their family, childcare responsibilities, and fear of unsafe workplaces.

CIDNY has supported legislation A2954 (Gunther)/S1032 (Rivera) the "safe staffing for quality care act" that would require acute care facilities and nursing homes to implement direct care nurse to patient ratios and minimum staffing requirements. CIDNY supports minimum care hours per nursing home resident, per day for Registered Nurses, Licensed Practical Nurses (LPNs), and Certified Nurse Assistants (Certified Nurse Assistants) with civil penalties for violation of these requirements. The minimum hours of care per resident, per day are as follows: RNs: 0.75 hours divided among all shifts to provide an appropriate level of RN care 24 hours per day, seven days a week; LPNs: 1.3 hours; and CNAs: 2.8 hours.

Involuntary discharges.

CIDNY believes that it has seen a pattern of discharges of residents that have a lower reimbursement rate in favor of higher paying residents. We believe that during the COVID pandemic nursing facilities have been further incentivized by the higher rates paid for COVID patients than for existing Medicaid residents. Most disturbing have been the discharges to homeless shelters, which should *never* be viewed as a safe discharge, especially during a pandemic. We estimate that about half of the facilities required to do this actually do. Between March 13 - July 28 we worked with individuals who received involuntary discharge notices to shelters. Many other residents may have been discharged during this time period without our knowledge.

- ***CIDNY has joined with other advocates in calling for a moratorium on involuntary discharges. CIDNY also supports A.10799 (Hevesi)/S.8764 (Rivera) which would establish additional requirements for the transfer, discharge and voluntary discharge from residential health care facilities.***

Lack of Personal Protective Equipment (PPE).

Nursing facility staff reported to CIDNY staff that they did not have adequate PPE. Residents wanted help, but staff were coming in without PPE and they had heard staff were infected, compromised.

We spoke with people with disabilities of all ages who were receiving home care but were terrified to let their home care workers in the door--despite the fact that they needed them desperately. They themselves and their workers lacked PPE.

- ***Health care facilities should have pandemic emergency plans which include detailed plans for (1) protecting residents, staff and visitors from infection and, (2) ensuring that the facility maintains or has access to at least a two-month supply of personal protective equipment without sharing, reusing, having only one for the day or other limitations. The plans should be tested to determine whether they will work in the event of an emergency.***

- ***CIDNY joins in supporting A10451 (Gottfried) / S8361 (Rivera) that would require insurance companies to reimburse the cost of PPE for homecare agencies.***

Communication.

One of the most disturbing features of the COVID-19 pandemic has been the blaming of nursing facility workers and the families of residents for the pandemic in nursing facilities. The most disturbing of all is the failure to maintain continuous contact between residents and their families, to ensure that all residents and families know that they can contact the Long-term Care Ombudsman.

During the pandemic residents and their families have been very frightened--discharging themselves against medical advice--without a plan--just to get out. There was no plan to screen those with a place to go and ability to put care in place to get them out.

People were calling CIDNY desperate to get out. We helped as many of them as we could and were able to get them services. However, it was difficult to get a social

worker on the phone and messages were not returned. Voluntary discharge planning appeared to be virtually halted for those seeking to exit.

While we were able to help 27 exit the nursing facility with services between March and July, we were working with some people who were then "taken away" and we did not know the status of what happened to them--then we found out they were dead. More than 136 people we were working with to transition to the community have died since March.

- ***If people with disabilities of all ages in nursing facilities are to be barred from being in the presence of their loved ones, a plan for a pandemic must include effective communication on a continuous basis between families and residents. Nursing facilities need to screen residents and permit families to work with the Open Doors Program to plan for expeditious transitions to the community for those able to leave without locating a residence*** *or facing other barriers.*

Chronic underfunding of the Long Term Care Ombudsman Program (LTCOP).

During the ongoing COVID-19 crisis, the Long Term Care Ombudsman Program (LTCOP)—a national, cost-effective federal volunteer program—has worked daily to provide needed assistance to residents of long term care facilities, serving as a set of eyes and ears to oversee these institutions and has been a critical resource for residents and their families. From March to July, staff and volunteers handled 350 complaints and requests for information. During March and April CIDNY staff heard many complaints on staffing shortages, infection control, lack of communication, lack of PPE and involuntary discharges.

A staff of 5 who have been trained and certified and trained and certified volunteers who work once a week visited and assisted residents of long-term care facilities before the crisis. They continue to do important work by facilitating communication with families and ensuring proper treatment of their loved ones, to the extent that has been possible under COVID-19 restrictions. Yet City Comptroller Scott Stringer found in a report issued June 17, 2020

In New York City there is only one ombudsman for every 8,650 nursing home residents, far below the recommendation by Institute of Medicine (IOM, now known as the National Academy of Medicine) of one full-time ombudsman for every 2,000 long-term care residents.

There are only 5 full-time paid ombudsmen and one volunteer coordinator assigned to visit the City's over 50,000 long-term care residents in 244 long-term care facilities.

There is no assigned ombudsman, whether full-time or volunteer, for over 20,000 residents in 80 long-term care facilities in the City.

The City has one-third of New York State's long-term care residents, yet the LTCOP managed by the Center for the Independence of the Disabled New York (CIDNY) receives less than one-seventh of the State's funding and no funding from the City.

In 2017, New York State spent less than $7.34 per resident bed on its LTCOP, while the remaining 49 states, on average, spent more than twice that amount: $14.70. The State spends less than $600,000 annually on the City's LTCOP.

New York's program is one of the most poorly funded in the nation. The State Comptroller previously released a report which also found that many residents in long-term care facilities lack representation from an Ombudsman due to lack of volunteers and paid staff. The report found that statewide, there are about half the recommended number of full-time staff. It found that in New York City alone, 23 more full-time staff would be required.

- ***For many years now, as the Executive budget has flat-funded the LTCOP program. CIDNY has called on the legislature to increase state share funding of the Long-term Care Ombudsprogram by $3 million.***

Create a concrete plan to shift the focus of long-term care to emphasize community-based care rather than institutional care.

New York has made use of the Open Doors/Money Follows the Person program to assist people who want to leave nursing facilities and has made small investments in an Olmstead housing subsidy to help people get the housing that is often the biggest barrier to getting out of a facility. The housing subsidy is low and it is difficult to locate housing that is affordable and accessible.

The State has at the same time reduced access to home care and long term services and supports necessary to remain in or return to the community. It is reducing one of the most popular sources of care for many, Consumer-Directed Personal Assistance.

- ***Additional resources for Open Doors programs and the Olmstead Housing Subsidy could help shift more individuals from nursing facilities to their own homes. Restore the Consumer-Directed Personal Assistance program.***

Imposition of severe cuts to home care hours through managed long-term care and reduced access to fair hearings.

New York's "Managed care for all" and the mandatory enrollment of dual eligible into Managed Long Term Care (MLTC) has also resulted in severe cuts to home care hours which have only been restored by requesting fair hearings against the MLTC.

A typical example would be a proposed cut of home care to 4 hours in the morning and 4 hours in the evening to a person who previously got 2 12 hour shifts 7 days a week of home care because they need to be turned and repositioned every two hours to avoid bedsores.

In response, New York has reduced access to fair hearings by requiring exhaustion of internal appeals and now hopes to allow Plans to reduce home care without a change in medical condition or change in circumstances simply because the enrollee is transitioning from one Plan to another due to the Plan that was providing adequate care withdrawing from the market.

This month over 20,000 people are being disenrolled from their Managed Long Term Care Plans due to a determination that they are "permanently placed". This, at a time when there is reduced ability to contest the determination with lack of access to family members or ombudsmen. The move to take people who require higher hours off the books of the MLTCs after three months if they are "permanently placed", is another incentive to institutionalize people, rather than provide adequate care in the community, and will be another barrier to getting out of a nursing facility.

The State has at the same time reduced access to home care and long term services and supports necessary to remain in or return to the community. It is reducing one of the most popular sources of care for many, Consumer-Directed Personal Assistance.

- ***Halt notices to nursing home residences and disenrollment until the pandemic is finished and more resources are available to assist residents, then allow more time and restore full access to fair hearings without exhaustion of internal appeals.***

Arbitrary limits on Medicaid Funded Personal Care Services and CDPAP.

The State adopted a Medicaid Design Team proposal to place an arbitrary limit on eligibility for Medicaid funded Personal Care Services and CDPAP to those people who require "limited assistance with physical maneuvering with three or more activities of daily living" (ADLs) with an exception for people with dementia or Alzheimer's, who could qualify for Medicaid personal care when they only require assistance with two or more ADLs.

The State imposed a 30 month "look-back" period on all asset transfers made by a person applying for Medicaid home care after October, 2020. The "look-back"period means that if an asset was sold or transferred for less than market value in the previous two and a half years, this can make the person ineligible for Medicaid for a period of time.

- ***CIDNY supports A10486 (Gottfried)/ S08403 (Rivera), legislation that would expand the categories of diagnoses that qualify an individual for personal care if, because of their impairments, they need supervisory or cueing assistance with ADLs.***

- ***CIDNY also supports A.10489 (Gottfried)/S.8337(Rivera) which would clarify that the 2 1/2 year lookback period for home care commencing in October 2020 would only look at transfers occurring after that date, list conditions that lessen the resulting penalty period, and enable home care to be provided under immediate need through attestation.***

Thank you for the opportunity to testify today. For further information, I can be contacted at sdooha@cidny.org.