Coalition Of Labor And Disability Advocates (COLADA)

June 22, 2020

Via email to gov.cuomo@chamber.state.ny.us

Dear Governor Cuomo:

We are the Coalition Of Labor And Disability Advocates (COLADA), a group of advocates for home care workers and home care consumers, united in our demand that New York State take immediate action to protect the health and safety of both home care workers, including Personal Assistants in the Consumer Directed Personal Assistance Program, and consumers. We acknowledge and thank you and your staff for your efforts to respond to the COVID-19 outbreak in New York – the epicenter of this global public health crisis. The outbreak has dramatically impacted the lives of every person in New York, and we appreciate that the tasks to address it are immense. But clear inequities have emerged in how the disease has affected people across the state, with vulnerable populations bearing the brunt of the virus. New York must take additional steps to center the needs of vulnerable New Yorkers including home care workers and home care consumers.

COVID-19 is killing Black and Latinx people at disproportionately high rates across the country and here in New York. Outside of New York City, 33% of New Yorkers who have died from COVID-19 have been Black or Hispanic, while they represent 21% of the population. In New York City, 62% of fatalities have been suffered by Black and Hispanic residents, who represent 51% of the New York City population. You have vowed to do the work needed to address the disparate impact COVID-19 has had on people of color. In your April 6th press conference you promised to research whether the number of Black and Latinx essential workers "who do not have a choice but to go out every day" have been put at greater risk. Home care workers, who are overwhelmingly immigrant women of color, are frontline health care workers who are more likely to be exposed to the virus. They are also caring for vulnerable people, many of whom are at high risk for severe illness or death if infected with the coronavirus. Despite this danger, home care workers have not been prioritized for testing and personal protective equipment (PPE), putting them and the people they provide services to at an even higher risk for infection.

Since the onset of the crisis, our organizations that represent home care consumers have experienced a sharp increase in cases reflecting a shortage of home care workers. In some cases, workers are ill and not able to come to work, or they are scared to work because of the lack of PPE. In some cases the consumers themselves are refusing services because of the lack of PPE.

¹ https://covid19tracker.health.ny.gov/views/NYS-COVID19-Tracker/NYSDOHCOVID-19Tracker-Fatalities?%3Aembed=yes&%3Atoolbar=no&%3Atabs=n

² https://www1.nyc.gov/assets/dca/downloads/pdf/workers/Lifting-up-Paid-Care-Work.pdf

When home care workers cannot come to work, consumers are faced with impossible choices between going without essential care or going to a nursing home or hospital.

We have always urged New York to provide sufficient funding for home care to ensure that seniors and people with disabilities can remain in their homes and communities in the most integrated setting, and to ensure that workers who provide personal care services to seniors and people with disabilities are paid for all hours that they work. These priorities are especially critical now. Congregate care settings such as nursing homes have proven to be deadly environments during this crisis. The rate of death of residents and staff of congregate care facilities is overwhelming and heartbreaking. As of April 23, 2020, in the 23 states that publicly report death data 10,000 residents and staff members of long term care facilities have died from COVID-19.³ In New York, more than 3,400 New York nursing home and adult care residents have died from COVID-19, with another 2,770 presumed to have died from the virus. 4 Keeping people in the community will protect all home care consumers, and it will also help to address racial disparities for people of color living with disabilities as reports show that the only distinguishing feature of nursing homes in New York that reported the highest number of deaths is the percentage of people of color who live there.⁵ New York must ensure that people have the supports and services they need to stay in the community and that workers have the pay and safe conditions needed to do their jobs.

Prior to this crisis, New York was already experiencing a troubling home care worker shortage. According to a 2019 Home Care Association of New York report, 17% of home health jobs across the state were unfilled. ⁶ As a result, 24% of people in need of home health aides could not access them and another 14.8% experienced delays in services. ⁷ This can be attributed in part to low wages, a lack of transportation, the difficulty of the job, and competition from other sectors where the jobs pose fewer challenges. If New York fails to ensure adequate pay and safe working conditions for home care workers during this pandemic, it will exacerbate the shortage of aides and personal assistants. It will also force people with disabilities into institutions at a time when hospitals are increasingly discharging patients to home care and nursing homes are trying to de-densify in an effort to control spread of the disease.

We have heard disturbing stories from our clients about how they are coping. Home care workers are wearing garbage bags that they or the home care consumer purchased with their own money when they are not provided with PPE. In New York City, home care workers have organized grassroots fundraising campaigns to purchase PPE for themselves and elected officials have donated masks. Consumers have asked their Medicaid managed care plans to provide PPE for themselves and their workers and have had those requests denied. Consumers have reported being scared to report problems for fear of being retaliated against by their managed care plans or home care agencies. Home care consumers who have tested positive for COVID-19 have reported that agencies are refusing to serve COVID-19 positive patients altogether or telling workers to bring their own PPE. Home care consumers who have tested positive for COVID-19

³ https://www.kff.org/medicaid/issue-brief/state-reporting-of-cases-and-deaths-due-to-covid-19-in-long-term-carefacilities/

⁴ https://www.health.ny.gov/statistics/diseases/covid-19/fatalities_nursing_home_acf.pdf

⁵ https://www.npr.org/2020/04/21/839522324/npr-analysis-of-covid-19-deaths-at-new-york-nursing-homes

⁶ https://hca-nys.org/wp-content/uploads/2019/02/HCA-Financial-Condition-Report-2019.pdf

⁷ *Id*.

have also found that workers were not told of their positive status. Two consumers reported that they were discouraged by a home care agency from disclosing their positive status to workers. This is unacceptable.

We are aware that the home care industry has also asked for the State to address the lack of PPE for home care workers. We support their recommendation that New York shift priorities to this sector and develop protocols to ensure appropriate distribution of PPE for home care workers.

The industry also recommended that New York allow Medicaid managed care plans to contact an enrollee to develop a voluntary change to their plan of care where insufficient PPE or staffing exists. We appreciate that the New York State Department of Health (DOH) has issued guidance reminding plans and local districts that Medicaid consumers may request a voluntary modification in their care plans, including a temporary reduction of hours or a change in days or times of services, which the guidance requires plans and districts to reinstate upon request within 72 hours. A voluntary reduction of hours is appropriate where family or community members are able and willing to provide informal support. However, we are concerned that consumers will be pressured into accepting "voluntary" changes in their care plans. We recognize that the aide shortage has created many unavoidably difficult situations, but care plans should not be changed at this time, even temporarily, unless a consumer has affirmatively requested the change based on reporting that they have alternative safe arrangements, and this has been confirmed in writing pursuant to the DOH guidance. Plans should be prohibited from reaching out to consumers about reducing services under a modified care plan if the consumer has not requested a reduction. We also strongly urge you to reject industry suggestions that Medicaid managed care plans be allowed to issue involuntary reductions in care without aid continuing rights and that plans and providers be given immunity from liability from harm resulting from such reductions. Not only do we believe this change would be unconstitutional, it is also immoral.

We ask that you take the following steps:

- o Require plans and agencies to provide testing and PPE for home care workers.
- Engage in oversight of agencies and plans to ensure that home care workers receive testing and PPE.
- o Require plans to provide PPE and in-home testing for home care consumers.
- o Ensure home care workers are paid for all hours worked.
- o Provide home care workers with premium pay during the emergency.
- Require plans and agencies to disclose a consumer's COVID-19 status to home care workers.
- o Require plans or agencies to provide car fare to home care workers.

⁸ Updated COVID-19 Guidance for the Authorization of Community Based Long-Term Services and Supports Covered by Medicaid, at 4, Apr. 4, 2020.

- o Publish data on home care consumer illness and death by COVID-19 disaggregated by race, primary language, disability status and zip code of the consumer.
- Publish data on home care worker illness and death by COVID-19 disaggregated by race, primary language, and zip code of the worker.
- Publish data on the number of home care consumers going without care or with fewer hours than those authorized disaggregated by race, primary language of the consumer and worker, and zip code of the consumer and of the worker.
- o Restore the Home Care Workforce Recruitment and Retention funding.

We thank you for your leadership and commitment to promoting the health and safety of New Yorkers. We urge you to do more to ensure the safety and well-being of home care workers and home care consumers. We would appreciate your prompt response. To discuss this matter further, please contact Belkys Garcia at (646) 581-4869 or brgarcia@legal-aid.org.

Sincerely,

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Center for Independence of the Disabled, NY
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Cc:

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