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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. August 10, 2020

Thank you for the opportunity to provide comments here today on behalf of the New York Association on Independent Living (NYAIL). NYAIL leads Independent Living Center efforts to eliminate physical and attitudinal barriers to all aspects of life and to fight for the civil rights and full independence of all people with disabilities. NYAIL and the network of Independent Living Centers (ILCs) provide an array of services assisting people to live at home as independently as possible with appropriate supports and services.

COVID-19 has only highlighted underlying problems that have long existed in nursing homes and other congregate care settings. Understaffing, poor infection control, and inadequate oversight and enforcement of these facilities has long been a problem that jeopardizes the health and safety of residents. These issues have only been exacerbated by the pandemic. There should be little doubt that these underlying deficiencies contributed to the crisis in these facilities over the past several months. We must ensure that if New York is once again hit hard by this virus, or another one, that a similar tragedy is prevented.

The State also has oversight of other congregate care facilities such as adult homes and group homes in addition to nursing facilities. We saw the same problems with lack of infection control and devastating numbers of people dying in these settings. However, the solutions to the problem may be different in an OPWDD group home than it would be for a nursing facility. It is equally important that the tragedy that occurred in those settings is prevented in the future and so we call on the State today to investigate what happened with COVID-19 in those settings.

One of the best ways to prevent this tragedy from reoccurring is to make home and community-based services easier to obtain and to make it easier for people to quickly transition out of these institutions in a crisis. This includes:

a. Require social services districts or Medicaid waiver programs to authorize services within 24-hours of the residents' request.

- Expedite approval for consumer directed personal assistance services, which is proving to be the most effective model of care for preventing and reducing infection rates.
- c. Ensure individuals have a place to go where they can self-quarantine and socially distance. Individuals who have family members or friends who can take them out of a facility, can move in with their families. For individuals who do not have a place to go, housing options should be made available to them in area hotels and college dormitories which are underutilized because of the COVID-19 pandemic as emergency housing.
- d. For individuals who have family members or other individuals that can provide personal assistance services, waive the rules that limit the ability of family members to provide personal assistance services under the program.
- e. To meet the needs of individuals who require agency-managed home care services, the state should immediately assess provider capacity for accepting new cases and refer these individuals based on that availability. Home care agencies will accept these cases upon referral and must not be permitted to refuse to serve these individuals. Where warranted to ensure adequate staffing allow Personal Care Aides to begin working with limited training.
- f. Fund community-based organizations like Independent Living Centers to assist with food and meals.
- g. All discharges from residential facilities must be voluntary. Individuals in nursing facilities should not be discharged or transferred against their will.

Collecting and making public data specific to state-funded facilities

The State needs to collect and release additional data related to the rate of infection in these facilities. Clarity is needed on the death rates in facilities, including those who are admitted to hospitals. Data should be available on the numbers of people who are infected on a given day to inform families and others. Further, the data related to the race of residents who are infected with the virus should be included to determine where there are health disparities based on race and ethnicity.

Access to Home Care

The State should be prioritizing access to home and community-based services as the answer to the tragic deaths in facilities during the pandemic. NYAIL has long advocated for better wages for home care workers. In many parts of the State, there is a home care shortage. This is primarily due to falling wages and disparate treatment of women and people of color who make up most home care workers. As wages increase in other sectors, such as fast food restaurants, it is increasingly difficult to find people willing to do this work which is physically and emotionally demanding. The State should increase

wages significantly for home care workers to ensure people have access to home care and are not unnecessarily institutionalized.

The State has also made cuts limiting access to home care that will push more people into facilities. In 2013, the State's own Olmstead Plan called for nursing homes to be carved into managed care to make it easier for people to transition out of institutions and into the community. Only a few years later, the State carved-out people who have stayed in a nursing facility for three months or more. This newly implemented benefit limitation will make it more difficult for people to transition out of institutions at a time when we need to prioritize community-based services. Implementation of this policy should be halted, especially during a pandemic.

This year's budget implemented several damaging proposals advanced by the Medicaid Redesign Team (MRT) II that will severely restrict access to home care and CDPA, despite the Governor's directive for the MRT's recommendations not to limit access to services.

The State is now implementing an arbitrary limit on access to home care, effectively eliminating Level I home care. This means that people will now have to require assistance with three or more activities of daily living, unless they have Alzheimer's or dementia, in which case they must require assistance with at least two ADLs. Eligibility as a result is based on diagnosis in part, rather than need. Further, it puts people who only require assistance with activities like cooking, cleaning, and shopping at risk as they will not have necessary supports to complete these activities that enable them to live in the community. This lack of assistance will lead to accidents, falls, and for some it will mean hospitalization with worse health outcomes as a result.

 NYAIL strongly supports A.10486 (Gottfried) / S.8403 (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.

The State also 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.

 NYAIL strongly supports A.10489 (Gottfried)/S.8337 (Rivera) which would clarify that the two and a half 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. NYAIL also strongly supports increasing funding for the Long-Term Care
Ombudsman Program (LTCOP) so that there is enough staffing to meet the
recommended ratio of one full-time staff ombudsman to 2,000 long-term care
residents.

If we learn anything from this crisis, it should be that institutionalizing people in an antiquated system of care that puts people's lives at risk is ethically and morally wrong. If the State acts now and properly invests in home care, fewer people will be forced to live out their 'golden' years in these institutional settings. Instead of seeing congregate care as cost containment through economies of scale, it's time to put people first and invest in professionalizing home and community-based services that allow people to live with dignity and respect.

Please feel free to reach out to me at 518-465-4650 or mparker@ilny.org.

Respectfully Submitted,

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