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July 20, 2020

Senator Charles E. Schumer  
322 Hart Senate Office Building  
Washington, D.C. 20510

Dear Senator Schumer,

The coronavirus has been devastating to the entire country, but it has hit nowhere as hard as its impact on people living in nursing facilities. The nursing facility population is only 0.4% of the country, but some estimates suggest these individuals comprise as much as 60% of all COVID-19 deaths. These deaths are being portrayed as "unavoidable" with states - including New York - making the case that the infections were brought into the facilities by staff and that the deaths were unrelated to the quality of care provided.

Based on what we know, with so many people living in such a confined space and requiring hands-on assistance, it would likely be very difficult to stop the virus, which - as Governor Cuomo described it - spread through nursing facilities like "fire through dry grass." A report for the state of New Jersey cited the 2018 deaths of 11 children in a New Jersey nursing facility from the spread of an adenovirus to illustrate their point that "Nursing homes are congregate settings that are the home for people prone to infection with weakened capacities to fight back." On this point, there is an unlikely agreement between disability rights advocates and nursing facilities, but our policy solutions are very different.

The public policy "solution" driven by states and nursing facilities has been to grant nursing facilities immunity from prosecution for COVID-19 deaths. Advocates, however, point to the fact that many elderly and Disabled individuals have no alternative to institutional placement because states - and managed care companies - control access to community-based services. This means that under current policy, states and managed care companies can force Disabled and elderly individuals into a facility where their lives will not be effectively protected from COVID-19 or other threats.

If we take steps so that institutions are protected from legal liability for these COVID-19 deaths, we must also take steps to protect elderly and disabled individuals so that they can avoid institutionalization in these facilities or leave these facilities if they are already institutionalized. In your portfolio of bills, you already have legislation that would do this. The Disability Integration Act (S.117-H.R.555), also known as DIA, would give disabled and older Americans at the institutional level-of-care a right to receive services and supports in the community as opposed to the institution.

Additionally, the Disability Integration Act includes specific language that would protect institutionalized individuals in the event of a future pandemic by giving them a right to secure community-based services based on an emergent basis. Specifically, Section 4(b)(7) states that "a failure to provide community-based services and supports, on an intermittent, short-term, or emergent basis, that assist an individual with an LTSS disability to live in the community and lead an independent life" is considered a form of discrimination. The language for this provision - suggested by Jennifer Mathis of the Bazelon Center - was originally intended to address the intermittent needs of people with mental health disabilities, but was carefully crafted to ensure that people who need LTSS in response to other emergent needs - like a natural disaster or pandemic - are also protected.

We are writing to urge you to push this bill (S.117/H.R.555) forward in the Senate and use your influence in the party to break the logjam the bill has faced in the House of Representatives where the bill languishes in committee even though we have more than a majority of members of the House signed on as cosponsors.

It is critical that Congress act now. As Congress considers next steps in responding to COVID-19, it must recognize that Disabled and older Americans are dying in record numbers in nursing facilities and other institutions. It must acknowledge the disproportionate effect this virus has taken on communities of color which has only served to deepen the existing disparities faced by Black and brown people, including those in nursing facilities.

We are happy to assist you in any way to move this bill forward, including helping identify ways to address any concerns or issues that have been raised. We are asking that you and your DC policy staff meet with us to discuss how we can work together to pass this bill. The meeting can be coordinated through our state association - the New York Association on Independent Living. Please contact Meghan Parker, Director of Advocacy, at [mparker@ilny.org](mailto:mparker@ilny.org) or 518-465-4650.

Minority Leader Schumer, we know you are committed to advancing the rights of people with disabilities - including New Yorkers with disabilities, and you are uniquely situated to address this crisis. We need a government that will not write off the lives of Disabled and older Americans and will protect all of us - including those in institutions - from this horrifying pandemic. With your leadership, we know that this is possible. As the late Justin Dart said, we need you to... "LEAD ON!"

Thank you in advance for using your influence to make DIA the legislative priority that we need it to be so that its language is included in Congress's response to COVID-19.

Sincerely,

Access To Independence of Cortland County  
AIM Independent Living Center  
Bronx Independent Living Services

Capital District Center for Independence  
Catskill Center For Independence  
Center for Disability Rights  
Center for Independence of the Disabled, New York  
Finger Lakes Independence Center  
Independent Living, Inc.  
Independent Living Center of the Hudson Valley  
Long Island Center for Independent Living  
Maximizing Independent Living Choices  
New York Association on Independent Living  
North Country Center for Independence  
Northern Regional Center for Independent Living  
Resource Center for Accessible Living  
Regional Center for Independent Living  
Rockland Independent Living Center, Inc. dba BRIDGES  
Southern Tier Independence Center  
Suffolk Independent Living Organization  
Taconic Resources for Independence, Inc.  
Tri-Lakes Center for Independent Living, Inc.  
Westchester Disabled On the Move, Inc  
Westchester Independent Living Center  
Western New York Independent Living