

May 16, 2020

Honorable Governor Phil Murphy:

Thank you for your excellent leadership in communicating with the public and acting decisively in our best interest throughout this unprecedented crisis.

The New Jersey disability community needs your assistance to achieve sustainable, short-, intermediary and long-term support to survive this pandemic and to thrive after it has passed. Below we identify seven critical issues that require immediate and decisive action:

- **Provide personal protective equipment (PPE) for personal care assistants (PCAs) and recipients of care and/or secure funding to reimburse these out-of-pocket expenses.**

PCAs employed through self-directed programs including Personal Assistance Services Program (PASP), Personal Preference Program (PPP), Managed Long-Term Services and Supports (MLTSS) and other Medicaid Home- and Community-Based Services Waiver Programs are not provided PPE. Although many people with disabilities and the elderly are insured by Medicare or Medicaid, these programs currently do not cover PPE-related expenses. The financial burden of paying for these scarcely available and costly life-protecting items must be borne by the recipients of care and/or their PCAs, many of whom have a limited income and often do not receive employer-provided health benefits.

PCAs are health care workers who enter homes to render “hands-on” personal care in situations where social distancing is not possible. Given the nature of their work, PCAs deserve the same level of protections as those required by hospital- and long-term care facility staff. If recipients of care are provided with PPE for their PCAs and/or funding to secure said items, inadequate supplies and the need to reuse equipment would be minimized. #WeAreEssential

- **Designate personal care assistants as essential workers and provide rapid, accessible and readily available COVID-19 testing for both symptomatic and asymptomatic PCAs.**

Many PCAs work multiple jobs in a variety of care-taking capacities at multiple locations and/or agencies to make ends meet. Long hours, close personal contact, and the often itinerant nature of their work puts PCAs at an increased risk to

contract and spread the virus whether or not they are exhibiting symptoms. It should also be noted that many home- and community-based services (HCBS) programs do not offer healthcare insurance to their workers, leaving PCAs with the financial burden of paying for PPE, doctor's visits and COVID-19 testing.

PCAs have close ties with an extremely vulnerable community; most individuals with disabilities who receive personal care services have underlying medical conditions. Designating PCAs as essential employees will also ensure recipients of care receive uninterrupted HCBS during emergencies, including road closures, evacuations and times when sheltering is necessary. #WeAreEssential

- **Appropriate funding sources for PCAs to receive, at minimum, their standard pay, when working with individuals with disabilities who are hospitalized for non-COVID-19 related conditions.**

People with disabilities should be able to retain PCA services for the duration of their hospital stay. Relying on overtaxed medical professionals who have been working in COVID-19 units puts lives at risk. PCAs are also typically familiar with the daily needs of the individual they support which provides an uninterrupted continuity of care that hospital staff are unable to provide.

Federal and state funding sources will allow PCAs to continue to earn, at minimum, their standard pay while working for their hospitalized clients, freeing up hospital staff to better care for COVID-19 patients. #WeAreEssential

- **Create an expedited process to safely relocate into the community the elderly and people with disabilities from congregate care facilities experiencing COVID-19 outbreaks.**

People living in congregate care facilities with disproportionately high rates of infection and subsequent mortality should be relocated into community settings with appropriate HCBS programs following either (a) a 14-day quarantine where the individual remains asymptomatic or (b) when the individual has tested negative for the virus. Recent reports confirm that congregate care facilities are dangerous petri dishes for viral outbreaks such as COVID-19.

Tighter and more frequent inspections of these facilities must occur to ensure they are minimally adhering to established and accepted infection-control protocols. It is unacceptable for the elderly and people with disabilities to continue to die unnecessarily simply because of where they live. #NoBodyIsDisposable

- **Increase the State's stockpile of ventilators to reduce care rationing and improve the quality of respiratory care for all New Jerseyans infected by COVID-19.**

Evidently, the private sector can not manufacture ventilators quickly enough to meet the current and/or potential demand for the respiratory care of the most critically ill COVID-19 patients. It is imperative that the State continue to request ventilators from the federal government.

While open-source ventilators are not yet ready for public production, investing in this type of research and development now will put the State in a position to receive this life-saving equipment as soon as it receives approval for widespread use.
#IncreaseTheSupplyOfVentilatorsNow!

- **Amend the *Allocation of Critical Care Resources During a Public Health Emergency* guidelines issued on April 11 as outlined in the [letter](#) addressed to Commissioner Persichilli from Disability Rights New Jersey (DRNJ) on April 16, as follows:**
 - Notify the individual patients about the allocation policy in use at the hospital when they arrive for emergent care.
 - Address the discriminatory disparate impact of the Sequential Organ Failure Assessment (SOFA) score and long-term survival standards on the aging and disabled populations who are being denied life-saving care on the basis of perceived outcomes.
 - Clarify the appeals process following an initial triage priority decision or the decision to withhold or withdraw scarce critical care resources.
 - Include standard operating procedures for the use of an individual's personal critical care equipment during a public health emergency.

The New Jersey Department of Health allocation guidelines should ensure the unabated death of people with disabilities and aging populations in the state does not continue! #NoBodyIsDisposable

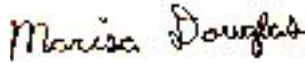
- **Include representatives from the disability community on *all* statewide task forces convened to address issues affecting New Jersey residents.**

The disabled civil rights community has a mantra: "Nothing about us, without us." Each and every one of the issues for which a statewide task force is created are also disability issues. Governor Murphy's Restart and Recovery Commission is no exception.

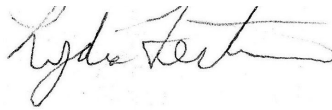
People with disabilities make up approximately 20 percent of the population in New Jersey and will play an integral role in the State's economic and social renewal. Having a voice in the decisions about our lives would go a long way in making members of the New Jersey disability community feel safe and valued.
#NothingAboutUsWithoutUs

As disabled residents of New Jersey, and contributing members of this great state, we urge you to prioritize the needs of at-risk New Jerseyans, including people with disabilities and the aging population. This unprecedented public health emergency has exposed the pre-existing scarcity of medical treatment, equipment and other resources available to the disability community. It is essential that these disparities are mitigated immediately, and as you prepare to reopen the State, so that the disability community has an equitable opportunity to thrive.

Sincerely,
Members of the New Jersey Disability Collective



Marisa Douglas



Lydia Fecteau



Millie Gonzalez



Anna Landre



Javier Robles



Colleen Roche



Norman Smith



Thomas Spadaro

CC: Lt. Governor Sheila Oliver
Commissioner Judith Persichilli
Commissioner Carole Johnson
New Jersey COVID-19 Task Force
Paul Aronsohn, Ombudsman for Individuals with I/DD and their Families