



## Via Email

August 31, 2020

The Honorable John C. Carney  
Governor of Delaware  
Carvel State Building  
820 North French Street  
Wilmington, DE

Dear Governor Carney:

In honor of the Americans with Disabilities Act's (ADA) 30th anniversary and in light of the lessons learned from COVID-19, the American Civil Liberties Union (ACLU) of Delaware, and Community Legal Aid Society of Delaware (CLASI), write to ask the Governor's Office to work with stakeholders to institute measures that will save the lives of some of the most at-risk members of our communities and the people who care for them. The Delaware Developmental Disabilities Council, State Council for Persons with Disabilities and Freedom Center for Independent Living endorse this letter.

We appreciate the steps your administration has taken thus far to protect long-term care residents and staff, such as increased testing and public reporting of COVID-related deaths in long-term care.

We urge you to consider additional steps to safeguard the health and safety of residents within institutional settings, to reduce the number of people in nursing homes and other congregate facilities for people with disabilities by transitioning them into community life, and to support and protect essential workers who care for seniors and people with disabilities regardless of setting.

COVID-19 continues to hit hard in nursing homes and long-term care institutions across the country and recent reports indicate that more than 71,000 residents and workers have died as a result, accounting for 42% percent of all deaths in the United States.<sup>i</sup> In Delaware, more than 60% of COVID-19 deaths are linked to long-term care facilities.<sup>ii</sup>

Segregated institutions can be dangerous and unhealthy for both residents and

staff, and the pandemic's impact on nursing homes reaffirms that without certain protective measures and enforcement, many vulnerable individuals are at risk. This view applies with equal force to other congregate institutions — intermediate care facilities for people with developmental and intellectual disabilities, psychiatric hospitals, and group homes — for which we have insufficient data but where workers' and residents' risk of infection and death may be just as high.

Because of the intimate nature of the work required in many congregate settings — assistance with feeding, bathing, dressing, and toileting — social distancing between staff and residents is impossible, and social distancing is impossible between residents who share a room. As a result, frontline workers, who are disproportionately women of color and immigrants, are at high risk of contracting COVID-19 and spreading it within their families and communities, which makes this issue not just a disability rights issue, but a race and gender issue as well. By taking the following crucial actions, you will help to safeguard the lives of people with disabilities, the workers who care for them, and the many Delaware families of both residents and staff.

## **A. Further Strengthen and Prioritize Community-Based Services**

Given the longstanding obligation under the Supreme Court's *Olmstead* decision to move people from institutions to the community,<sup>iii</sup> and given the heightened public health hazard that these congregate settings are proving to be for residents and the workforce, the state must step up its efforts to reduce the number of people in nursing homes and congregate facilities for people with disabilities. We urge the Governor's Office to take the following steps.

### **1. Prioritize and Expand Home and Community - Based Services**

According to the latest available data, Delaware devotes only 48% percent of its Medicaid Long-Term Services and Supports expenditures on Home and Community Based Services ("HCBS"), lower than the national average.<sup>iv</sup> HCBS services are especially important during and after the pandemic, which has made the dangers of institutional life even more clear. These funds are necessary to sustain the workforce that supports people with disabilities, the service providers that employ that workforce, and the people with disabilities who rely on those services to live safely in their homes and communities. Delaware should re-invigorate services provided under the Money Follows the Person program, now folded into the Medicaid Managed Care system. This critical component is lacking in transparency, goals and data. A robust and directed program with deliverables will make transition to the community both more likely and more successful.

### **2. Assess the Status of Residents in Psychiatric Inpatient Facilities**

Aggressive action is necessary to reduce the number of people confined in inpatient facilities across the state, including the Delaware Psychiatric Center, which has had at least one very serious outbreak already.<sup>v</sup> Officials at DPC and

other inpatient facilities should require the facilities to certify and report immediately that they have engaged in an individualized assessment and re-evaluation of residents under their care in order to assess who can be discharged and what supports are required to live in the community. Officials should also ensure adequate supplies of PPE and verify that all staff members have adequate training.

Our recommendations on inpatient facilities include any facilities that house juveniles as well. Patients, family members, and staff deserve immediate action to improve the current situation at inpatient facilities at every level in Delaware.

The federal government's Substance Abuse and Mental Health Services Administration (SAMHSA) has urged, with respect to admissions, that "[b]ecause of the substantial risk of coronavirus spread with congregation of individuals in a limited space such as in an inpatient or residential facility... outpatient treatment options [should] be used to the greatest extent possible. Inpatient facilities should be reserved for those for whom outpatient measures are not considered an adequate clinical option, i.e., for those with mental disorders that are life-threatening, (e.g., the severely depressed suicidal person)."<sup>vi</sup>

Additionally, discharges should be accelerated. To facilitate a decrease in the psychiatric inpatient population, the state should increase its support of community providers of outpatient mental health treatment. Restrictions on telemedicine have largely been lifted. However, community providers, already strapped before the pandemic, need additional funding and greater access to technology and PPE. Ensuring robust community-based crisis treatment, community supports, and integrated housing settings will reduce the need for psychiatric hospital and other inpatient facilities admissions and enable more patients to safely return to their communities, which is also in line with the ADA and the *Olmstead* decision to eliminate segregation and to provide the most integrated setting based on an individual's needs.<sup>vii</sup> Moreover, in many cases, families will offer to temporarily house and care for relatives being discharged from or not admitted to an inpatient facility if sufficient, reliable support is available from community providers.

Given the urgency of the situation, we ask that your office provide an expedited public report on the steps that have already been taken or that will be taken to address these concerns on behalf of people confined at inpatient facilities throughout the state.

3. Grant Advocacy Organizations Access to Facilities in Order to Assess Residents' Ability to Transition into the Community

Many nursing homes have instituted lockdowns that prevent family members and advocacy groups from gaining access to residents. While this measure may be necessary to limit transmission of infections, Delaware should not block long-Term Care Ombudsman staff and other agencies such as CLASI who have access authority to investigate and monitor settings with people with disabilities.

4. Support Family Members Providing Care

Family caregivers play a central role in helping seniors and people with disabilities live in their homes and communities, rather than institutions. For instance, 80 percent of people with an intellectual or other developmental disability live with a caregiver who is a family member.<sup>viii</sup> And more than 40 million family caregivers provide unpaid care each year.<sup>ix</sup> But the economic, logistical, and health challenges faced by caregivers are only exacerbated by COVID-19, especially as infection spreads and creates new caregiving needs. While Delaware has elected in its Appendix K waiver request to allow spouses and parents of minor children to provide personal care services, it should expand the ability for family members other than spouses and parents to be paid for caregiving responsibilities. Delaware should fund, with state dollars if necessary, retainer payments to community providers so that meaningful community-based programs are available when COVID restrictions are lifted. Infrastructure to support community employment and activities needs to be maintained for future needs.

## **B. Protect Residents in Nursing Homes and Other Large Congregate Facilities for People with Disabilities**

### **5. Expanded Data Collection and Transparency**

Delaware's data collection and transparency effort regarding congregate settings needs improvement. The COVID-19 data site contains information regarding total numbers of cases at long-term care facilities is simply insufficient. Delaware must mandate daily, public reporting of both resident and staff cases and deaths in each long-term care facility, as well as other congregate settings, including psychiatric hospitals, intermediate care facilities for individuals with intellectual disabilities, and group homes and supervised living arrangements, with due regard to privacy.

Across the nation, disability rights and workers' rights groups have been sounding the alarm about the lack of attention and resources devoted to residents and workers in these facilities<sup>x</sup> and we join them in expressing grave concern. Nationally, available data suggest that case fatality rates in intermediate care facilities for people with developmental disabilities, group homes, and psychiatric facilities are also far higher than for the general population.<sup>xi</sup> The crisis requires more public data, transparency, and swift and concerted action by government leaders.

Therefore, we urge the Governor's Office to enact the following measures: release to the public the state's plan to address COVID-19 in long-term care facilities, ensure that all nursing homes are complying with required data collection, require all congregate facilities for people with disabilities, *not just nursing homes*, to report to the Delaware Department of Health and Social Services (DHSS) information about facility COVID-19 policies/protocols/plans, testing, PPE supplies, staffing levels, discharges and evictions, positive cases and deaths of residents and workers in each facility. Failure to require comprehensive data conceals from the public the full scope of the problem, and thwarts critical attempts to design and implement policies that will protect seniors, people with disabilities, and the people who care for them.

Data for all these facilities must be publicly available and posted on DHSS' COVID-19 data dashboard, and include demographic breakdowns by race, ethnicity, sex, primary language, disability status, and age for infections, deaths, discharges, and evictions.

#### 6. Conduct On-Site Monitoring for Abuse and Neglect

Residents of nursing homes and other congregate facilities for people with disabilities face a heightened risk of abuse and neglect during the pandemic, when their families and friends outside the facility cannot maintain the same level of in-person contact they would ordinarily enjoy. However, preventing the spread of COVID-19 should not mean that we ignore abuse and neglect. We urge you to do more. Specifically, we urge state agencies like DHCQ, DPH and Adult Protective Services to conduct routine, on-site monitoring of facilities, with appropriate PPE provided. Outside advocacy organizations should also be allowed monitoring access, and family members should be allowed into facilities, with appropriate precautions, so they can lay eyes on their family members and on the facilities.

### **C. Support Direct Service Professionals and Workers in Congregate Facilities Who Care for Seniors and People with Disabilities**

Delaware must do all in its power to meet the needs of essential workers who, at great risk to themselves, their families, and their communities, are showing up every day to care for and assist vulnerable seniors and people with disabilities. Nationally, nearly 90 percent of nursing, psychiatric, and home care aides in the United States are women<sup>xii</sup> and 23 percent are immigrants.<sup>xiii</sup> Black women are over-represented in the congregate care workforce.<sup>xiv</sup> And overall, the majority of women working as home health and personal care aides are women of color whose economic security is already precarious due, in part, to systemic racism that has long devalued caregiving<sup>xv</sup> and fueled poverty-level wages.<sup>xvi</sup> All workers in the state deserve greater workplace benefits and protections but during this pandemic, and the state should step forward and prioritize the needs of these essential frontline workers. Many of these workers have to take multiple such jobs to make ends meet, meaning one positive worker could spread COVID at multiple homes/facilities.

#### 1. Provide Personal Protective Equipment for Workers

Delaware must ensure that direct service professionals providing HCBS, workers providing services under state-funded personal attendant programs *and* workers in congregate facilities have the necessary supply of PPE including gowns, N95 facemasks, gloves, hand sanitizers, and eye protection (i.e. face shields or goggles). The PPE shortages experienced by nursing homes nationally have been well documented but the situation facing workers in other settings is dire and must be prioritized. Without innovative and aggressive action to procure PPE, seniors, people with disabilities, and workers and their family members will be at grave risk of infection, illness, and even death. It should go without saying that these needs should

be addressed now, before fall and winter months make outbreaks more likely.

2. Provide Paid Leave to Workers in All Settings

Delaware should provide at least two weeks of guaranteed paid sick leave to allow workers to care for themselves or family members for the duration of the public health emergency. The spread of COVID-19 has highlighted the health and economic consequences faced by working people when they lack access to paid sick days and paid family and medical leave. In the United States, 33.6 million workers lack access to paid sick days.<sup>xvii</sup> While 93 percent of the highest-wage workers have access to paid sick days, only 30 percent of the lowest wage workers do, including the men and women who care for seniors and people with disabilities in facilities and in communities. Too many workers must choose between risking their own health (and that of their families and communities) and risking the loss of a paycheck or job. No one should face this choice, let alone during an unprecedented public health emergency.

3. Increase Worker Pay and Provide Alternate Housing

Delaware should increase workers' pay and offer alternative housing to workers, as other states have done, especially those in COVID-positive facilities who do not want to return home and risk exposing their families to COVID-19. As stated above, our state should use CMS waivers or state plan authorities to pay overtime rates to workers at congregate settings during this crisis as hazard pay or compensation for dangerous working conditions. We should also seek authorization for temporary supplemental pay increases to direct service professionals providing HCBS and for overtime pay by lifting caps on the number of hours workers may provide HCBS. Protecting workers by providing PPE, paid sick leave, increased hazard pay, and alternative housing is smart for Arizona families, our communities, and our economy.

**D. Do not grant immunity to long-term and intermediate care facilities.**

Do not grant immunity from COVID-19 related suits to congregate facilities. COVID-19 does not relieve facilities from the responsibility of taking all reasonable protective measures to safeguard the health and well-being of staff. The closure of these facilities to visitors and lack of routine licensing visits has made it even more difficult to assess whether facilities followed standards of care during the pandemic. In the current vacuum of facts and information, it would be unconscionable to prevent injured parties and their families from having access to regular avenues for seeking redress and exposing negligence.

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Delaware and our nation are facing unprecedented challenges. In this moment, we have been called to come together against a pandemic that has taken the lives of many, but also against long-entrenched biases that marginalize people with

disabilities, and against systemic racism that has deeply wounded and killed more than we will ever know. In these instances, people with disabilities and Black, Indigenous, and Latinx people have paid a steep price. We can begin to strike a blow against these scourges by implementing the policy proposals outlined in this letter. These recommendations will not only help to protect the lives of seniors and people with disabilities, but also greatly benefit the Black and Brown workers (and their families) who comprise the majority of the workforce in congregate facilities and HCBS programs.

Thank you for your consideration. We welcome the opportunity to discuss these proposals with you and members of your administration.

Sincerely,

/s/ Mike Brickner  
Mike Brickner,  
Executive Director  
ACLU of Delaware

/s/ Laura Waterland -  
Laura Waterland  
Disabilities Law Project Director  
Community Legal Aid Society of Delaware

cc: Secretary Molly Magarik, DHSS  
John McNeil, Director SCPD  
Kristin Harvey, Director DDC  
Patricia Maichle, Director FCIL

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<sup>i</sup> The COVID Tracking Project *available at* <https://covidtracking.com/data/longtermcare>.

<sup>ii</sup> *Id.*

<sup>iii</sup> *Olmstead v L.C.*, 527 U.S. 581, 600-01(1999) (recognizing that “unjustifiable institutional isolation of persons with disabilities is a form of discrimination”...that “confinement in an institution severely diminished the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment”...and that such confinement “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”).

<sup>iv</sup> Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*, Medicaid Innovation Accelerator Program (May 2018), *available at*

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<https://www.medicaid.gov/sites/default/files/2019-12/ltssexpenditures2016.pdf>.

<sup>v</sup> <https://news.delaware.gov/2020/04/08/dhss-announces-positive-cases-involving-patients-and-staff-at-delaware-psychiatric-centerdpc/>

<sup>vi</sup> Substance Abuse and Mental Health Services Administration, *Considerations for the Care and Treatment of Mental and Substance Use Disorders in the COVID-19 Epidemic* (March 20, 2020, revised May 7, 2020), available at <https://www.samhsa.gov/sites/default/files/considerations-care-treatment-mental-substance-use-disorders-covid19.pdf>.

<sup>vii</sup> U.S. Dep't of Justice, Civil Rights Division, *Olmstead: Community Integration for Everyone*, available at <https://www.ada.gov/olmstead/>.

<sup>viii</sup> The Arc, *New Data Reveals Our Nation Is Failing to Support People With Intellectual and Developmental Disabilities* (June 12, 2018), available at <https://thearc.org/new-data-reveals-nation-failing-support-people-intellectual-developmental-disabilities/>.

<sup>ix</sup> National Council on Aging, *Issue Brief: Support Family Caregivers and Home and Community-Based Services* (March 2016), available at <https://d2mkcg26uvvg1cz.cloudfront.net/wp-content/uploads/IB16-Family-Caregivers-and-HCBS-March.pdf>.

<sup>x</sup> Holbrook Mohr et al., *Thousands sick from COVID-19 in homes for the disabled*, Associated Press (June 11, 2020), <https://apnews.com/bdc1a68bcf73a79e0b6e96f7085ddd34?>

<sup>xi</sup> See, e.g., Joseph Shapiro, *COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities*, NPR, (June 9, 2020), <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disability>; Ill. Dep't of Human Servs., *COVID-19 Confirmed Positive Cases* (last updated June 19, 2020), available at <https://www.dhs.state.il.us/page.aspx?item=123651>.

<sup>xii</sup> AARP Public Policy Institute, *Women & Long-term Care (Fact Sheet)*, available at [https://assets.aarp.org/rgcenter/il/fs77r\\_ltc.pdf](https://assets.aarp.org/rgcenter/il/fs77r_ltc.pdf).

<sup>xiii</sup> Leah Zallman et al., *Care for America's Elderly and Disabled People Relies on Immigrant Labor*, 38 *Health Affairs* 919, 923 (2019), available at <https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.05514>.

<sup>xiv</sup> Timothy Bates et al., *Racial/Ethnic Diversity in the Long-term Care Workforce*, University of California San Francisco Health Workforce Research Center on Long-term Care (April 18, 2018), available at [https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/REPORT-2018.HWRC\\_diversity\\_4-18.pdf](https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/REPORT-2018.HWRC_diversity_4-18.pdf).

<sup>xv</sup> Ariela M. Migdal, *Home Health Care Workers Aren't Guaranteed Minimum Wage or Overtime, and the Legacy of Slavery Is the Reason Why*, HuffPost (Updated May 6, 2016), [https://www.huffpost.com/entry/home-health-care-workers\\_b\\_7224080?guccounter=1](https://www.huffpost.com/entry/home-health-care-workers_b_7224080?guccounter=1).

<sup>xvi</sup> Maya Raghu & Jasmine Tucker, *The Wage Gap Has Made Things Worse for Women on the Front Lines of COVID-19*, National Women's Law Center (March 30, 2020), available at <https://nwlc.org/blog/the-wage-gap-has-made-things-worse-for-women-on-the-front-lines-of-covid-19/>; Sarah True et al., *COVID-19 and Workers at Risk: Examining the Long-Term Care Workforce*, Kaiser Family Foundation (April 23, 2020), available at <https://www.kff.org/medicaid/issue-brief/covid-19-and-workers-at-risk-examining-the-long-term-care-workforce/>.

<sup>xvii</sup> Drew Desilver, *As coronavirus spreads, which U.S. workers have paid sick leave – and which don't?*, Pew Research (March 12, 2020), available at <https://www.pewresearch.org/fact-tank/2020/03/12/as-coronavirus-spreads-which-u-s-workers-have-paid-sick-leave-and-which-dont/>.