October 19, 2020
The Honorable Henry McMaster
State House
1100 Gervais Street
Columbia, South Carolina 29201

Dear Governor McMaster:

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 South Carolina, Protection and Advocacy for People with Disabilities, Inc. (P&A), the South Carolina Women’s Rights and Empowerment Network (SC WREN), Able South Carolina (Able SC), AARP South Carolina, and YWCA Greater Charleston write to ask the Governor’s Office to work with stakeholders to institute measures that will save the lives of institutionalized people with disabilities that are at the highest risk of negative health outcomes from COVID-19 as well as the people who care for them.

Since President George H.W. Bush signed the ADA, an important civil rights law, people with disabilities have seen improved access to critical programs and services, and many have successfully advocated for their rights, notably seen in the 1999 Olmstead decision that clarified institutionalization as discrimination. However, despite all of our success as a nation, people with disabilities still face institutionalization at high rates, leading to increased risk of COVID-19 transmission and death.

We urge the Governor’s Office to swiftly enact policies 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. In order to achieve that critical transition from institutions to the community, South Carolina must also prioritize efforts to support Home and Community Based Services (HCBS), Money Follows the Person, healthcare workers, paid care givers, and other essential employees.

In this letter, we outline the following steps that will help achieve these goals and urge you to implement these actions as soon as possible:

- Further strengthen and prioritize community-based services by:
  - Continuing to prioritize and to expand home and community-based services programs;
  - Assessing the status of residents in facilities, particularly psychiatric inpatient facilities;
  - Creating a South Carolina Olmstead Plan, including opportunities for housing, transportation, and employment;
Supporting advocacy organizations’ mandated access and community integration efforts;
- Supporting family members providing care.

- Protect residents in nursing homes and other congregate facilities by:
  - Expanding data collection and transparency;
  - Provide further support for on-site monitoring for abuse and neglect and education on the rights of residents.

- Support direct service professionals and workers in congregate facilities by:
  - Continuing to ensure workers have personal protective equipment;
  - Providing paid leave to workers in all settings;
  - Increasing worker pay and providing alternative housing.

These action steps are needed more than ever because of the pandemic. COVID-19 is raging through nursing homes and long-term care institutions across the country and recent reports indicate that more than 72,000 residents and workers have died as a result, accounting for more than 35 percent of all deaths in the United States. These statistics have shocked not only the healthcare community, but individuals and loved ones who live and work in these facilities. South Carolina has not been spared; we have seen nearly 1,400 deaths among residents and staff of long-term care facilities since April 3, representing about 40 percent of deaths overall in the state.

Segregated institutions are dangerous and unhealthy for both residents and staff, and the pandemic’s impact on nursing homes – including the 194 nursing homes and 40,000 residents and workers in South Carolina – 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 the same is true 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 the coronavirus 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 South Carolina families of both residents and staff.

A. Further Strengthen and Prioritize Community-Based Services

South Carolina operates seven Home and Community Based Services (HCBS) waivers which provide critical services that enable people with disabilities to avoid institutionalization and thrive in the community. Access to these waivers has been continuously inhibited by years-long waiting lists, which South Carolina must remedy by allocating additional funds to create new waiver slots and reduce the waiting lists. Additionally, when the pandemic began, South Carolina applied for numerous waivers to prepare for the care and treatment of those who would be affected by the pandemic. However, additional waivers would further combat COVID-19 and improve outcomes for people with disabilities.

Given the longstanding obligation under the Supreme Court’s *Olmstead* decision to move people from institutions to the community, 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 HCBS

According to the latest available data, South Carolina devotes 49 percent of its Medicaid Long-Term Services and Supports expenditures on HCBS, below the national average. VI 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. States across the country, including South Carolina, have sought approvals from the U.S. Centers for Medicare & Medicaid Services (CMS) for section 1915(c) waiver Appendix K changes that have made it easier to access home and community-based services. VII South Carolina should also retain the positive changes achieved by Appendix K waivers as permanent changes to the HCBS waivers themselves.

South Carolina has not taken full advantage of the flexibilities under the Appendix K waiver, including increasing payment rates and ensuring family members or legally responsible individuals can be paid as caregivers. It should do so. Other options, such as Community First Choice waivers, alternatives to hospitalization like “Hospital at Home” programs, VIII emergency personal assistance registries, and cohorting in alternative housing while transitioning to the community, IX should also be used to supplement HCBS in order to reduce the institutional population.

Finally, to assist South Carolina in providing HCBS services, we urge the state to seek available funding recently announced by CMS for the state’s Money Follows the Person program, which is essential in helping transition people with disabilities and older adults from institutions into their homes and communities. X You should also encourage the state’s U.S. Senators to provide additional support through Federal Medical Assistance Percentage (FMAP) increases in the next COVID-19 relief package that Congress passes, including an HCBS-specific FMAP increase in order to defray the cost of these programs and avoid cuts in the future.

2. Assess the status of residents of congregate facilities, prioritizing psychiatric facilities

Aggressive action is necessary to reduce the number of people confined in congregate facilities across the state, including the hospitals and veterans’ nursing homes operated by the South Carolina Department of Mental Health (DMH). XI The Department of Health and Environmental Control (DHEC), the Department of Health and Human Services (DHHS), the Department of Disabilities and Special Needs (DDSN), and DMH should require facilities to certify and report immediately that they have engaged in a conflict-free, 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. Such discharge planning assessments must occur regularly. Officials should also continue to ensure adequate supplies of PPE and verify that all staff members have adequate training. Our recommendations on congregate 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 South Carolina.

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).” XIX This standard must be applied in all psychiatric inpatient facilities until testing of patients and staff is widely done and safe isolation practices and social distancing protocols are in place.

Additionally, transitions out of institutions 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 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.\textsuperscript{xiv} Moreover, in many cases, families will offer to temporarily house and care for relatives being discharged from or not admitted to hospitals. More families will do so if support is available from community providers.

Given the urgency of the situation, we ask that you 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. **Create a South Carolina Olmstead Plan**

Ending over-institutionalization cuts against financial motivations of the institutions themselves. Through planning and oversight from individuals with disabilities, their family members, legal rights organizations, and community-based service providers, solutions can be furthered that incentivize community-based services while penalizing organizations that continue to keep clients from accessing those services and moving into less restrictive settings.

According to 2013’s decennial report on the outcomes following Olmstead, 25 states have created an Olmstead compliance plan or have made meaningful steps towards creating such a plan, but South Carolina is not included.\textsuperscript{xv} For more than 20 years, the State of South Carolina has not made a measureable effort to address the discrimination made clear by the Olmstead decision. South Carolina’s failure to enact an Olmstead Plan and reduce the number of people living in congregate settings contributes to the now higher risk of COVID-19 transmission and death brought about by the inappropriate institutionalization of people with disabilities. South Carolina’s Olmstead Plan must include a strong commitment to affording people with disabilities opportunities to secure accessible and affordable housing, transportation, and fully integrated employment. The plan must therefore include identifiable benchmarks that the state should achieve to further these commitments.

4. **Support advocacy organizations’ mandated access and community integration efforts**

Since the COVID-19 pandemic began, nursing homes and other long term care facilities 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, South Carolina should support Protection and Advocacy’s access, not only to exercise its authority to investigate and monitor settings with people with disabilities, but also to offer outreach with other advocacy organizations that educate residents and staff about the rights of people with disabilities, including the right to community integration.\textsuperscript{xvi}

South Carolina should also honor the Bill of Rights for Residents of Long-Term Care Facilities, and allow residents visitation and communication with South Carolina’s Centers for Independent Living (Able South Carolina, AccessAbility, and Walton Options for Independent Living) and other providers with expertise in and a mandate to transition people from institutions to the community.\textsuperscript{xvii} This will allow these groups to work directly with residents in congregate facilities, either in-person (with appropriate PPE provided) or via videoconference, to offer assistance for relocating and an assessment of each person’s desire to move to a safer location, either temporarily or with the option to make a permanent transition to the community.\textsuperscript{xviii} Allowing visitation, communication, and general access to residents for the Centers for Independent Living and other providers will help reduce the census in long term care facilities, and reduce future exposure to COVID in congregate settings.

5. **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.\textsuperscript{xix} And more than 40 million family
caregivers provide unpaid care each year. 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. South Carolina should update its Appendix K waiver requests to CMS to allow payment to family members and legally responsible individuals for caregiving. The state should also take steps to support both paid and unpaid family caregivers by developing and offering robust and culturally appropriate services, including caregiver assessments to help improve targeting of supportive services, caregiver training, respite, counseling home-modification and assistive technologies.

B. Protect Residents in Nursing Homes and Other Congregate Facilities for People With Disabilities

1. Expanded data collection and transparency

It is clear that South Carolina recognizes the need for reporting on congregate settings. The state’s dashboard includes facility-level data on cases and deaths, for both residents and staff, for a range of facilities that includes nursing homes, assisted-living facilities, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID), and psychiatric residential treatment facilities (PRTFs). It also maps active and inactive outbreaks by county and facility type. We recommend even more improved reporting so that those affected by these issues can make better decisions to control and limit COVID-19 infections and prevent deaths. The state’s reporting does not include all congregate facilities in these classes that fall under the state’s oversight, including group homes for children licensed by the Department of Social Services, psychiatric hospitals and other residential settings for individuals with developmental disabilities. It should.

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 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. In South Carolina, there are more than 1,100 people in Community and Regional Intermediate Care Facilities, more than 1,500 people served by state psychiatric hospitals, and an unknown number of others in inpatient congregate settings who are all at heightened risk. 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 to report to DHEC information about facilities’ 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.

The state should also provide other vital data, including demographic data specific to all congregate settings for people with disabilities that includes race, ethnicity, sex, primary language, disability, and age for infections, deaths, discharges, and evictions. Maintaining demographic data – as the state does for the general population’s total number of cases, hospitalizations, and deaths by race/ethnicity, age, and gender – helps assess the impact on vulnerable populations.

The effect of COVID-19 has landed disproportionately on people with disabilities, women, and Black, Indigenous, and Latinx people. Recent reporting shows that while about 14 percent of nursing home residents nationally are Black and five percent are Latinx, nursing homes with predominantly Black and Latinx residents — regardless of government rating, size or location — “were twice as likely to get hit by the coronavirus as those where the population is overwhelmingly white.” Race and ethnicity data that we do
have for South Carolina underscores this point. Black people account for nearly 44 percent of hospitalizations and 35 percent of the state’s reported COVID-19 deaths\textsuperscript{xxx} while making up about a quarter of the state’s population.\textsuperscript{xxx}

All nursing home residents are people with disabilities, and nearly 70 percent are women.\textsuperscript{xxxi} As we detail below, the workforce in South Carolina caring for people in nursing homes and other congregate settings for people with disabilities is disproportionately women of color. More robust demographic reporting is needed to determine how COVID-19 is disproportionately affecting these overrepresented populations.

2. Additional support of 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. By supporting P&A access to facilities and recognizing the rights and community integration efforts of the advocacy groups, as described above, South Carolina will improve its ability to uncover and address abuse and neglect while also moving more people into the community. This will also reduce the numbers of people who could be exposed to COVID-19.

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

South Carolina 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\textsuperscript{xxxi} and 23 percent are immigrants\textsuperscript{xxxiii} Black women are over-represented in the congregate care workforce.\textsuperscript{xxxiv} 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\textsuperscript{xxxv} and fueled poverty-level wages\textsuperscript{xxxvi}. In South Carolina, these figures are similar. Sixty-four percent of the nearly 50,000 direct care workers are Black, and 93 percent are women.\textsuperscript{xxxvii} Direct care workers’ media annual earnings were less than $16,000, and 44 percent relied on some type of public assistance.\textsuperscript{xxxviii} All workers in the state deserve greater workplace benefits and protections but during this pandemic, the state should step forward and prioritize the needs of these essential frontline workers.

1. Provide personal protective equipment for workers

South Carolina must ensure that direct service professionals providing HCBS \textit{and} workers in congregate facilities have the necessary supply of PPE including gowns, N95 facemasks\textsuperscript{xxxix} gloves, hand sanitizers, and eye protection (i.e. face shields or goggles).\textsuperscript{xl} The PPE shortages experienced by nursing homes have been well documented\textsuperscript{xli} but the situation facing workers in other settings is dire\textsuperscript{xlii} 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.

2. Provide paid leave to workers in all settings

South Carolina 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.\textsuperscript{xliii} 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**

South Carolina should increase workers’ pay and offer alternative housing to workers, as other states have done, especially those in COVID-positive facilities who don’t 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 South Carolina families, our communities, and our economy.

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South Carolina 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 warehouse 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,

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cc: Joshua D. Baker, Director, Department of Health and Human Services  
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v 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.”).


vii South Carolina should be prepared to request renewal of the Appendix K waivers before the January 26, 2021 expiration date.


xvi Protection and Advocacy for People with Disabilities, Inc. is the designated Protection and Advocacy system of South Carolina and has authority to monitor facilities, investigate allegations of abuse and neglect, and educate residents and staff of the rights of people with disabilities. 42 C.F.R. § 51.42(c) (Protection and Advocacy for Individuals with Mental Illness Act regulations, authorizing Protection & Advocacy access for the purpose of “monitoring compliance with respect to the rights and safety of residents”); 45 C.F.R. § 1326.27(c)(2)(ii) (Developmental Disabilities Assistance and Bill of Rights Act of 1975 (DD Act) regulations, authorizing the same); 29 U.S.C. § 794e(f)(2)) Protection and Advocacy for Individual Rights Act, granting same authorities as set forth in the DD Act.

xvii The Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunity Act of 2014, 29 U.S.C. 32, mandates Centers for Independent Living provide a set of core services that include facilitating the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based settings.

xviii We recognize Protection & Advocacy systems (P&As) have access authority pursuant to 42 CFR 51.42 (access authority for protection & advocacy agencies for individuals with mental illness) and 45 CFR 1326.27 (access authority for protection
and advocacy agencies for individuals with developmental disabilities). P&As and facility staff should work together to ensure effective monitoring while recognizing and staying compliant with federal, state, and facility safety guidelines.


xxii Holbrook Mohr et al., Thousands sick from COVID-19 in homes for the disabled, Associated Press (June 11, 2020), https://apnews.com/6bc168b6bc7a79e06e8f7085dd342.


xxvi DHEC, Nursing Homes & Extended Care Facilities Impacted by COVID-19.


xxix DHEC, South Carolina County-Level Data for COVID-19 (see Reported COVID-19 Deaths, by Reported Race; Hospitalized COVID-19 Cases, by Race. Data as of state’s Oct. 12, 2020 update)

xxx United States Census Bureau, QuickFacts South Carolina, available at https://www.census.gov/quickfacts/SC.


xxxvii PHI, Workforce Data Center, http://phinational.org/policy-research/workforce-data-center/ (see Race and Ethnicity, Gender for South Carolina under State Data)

xxxviii Ibid (see Earnings, Public Assistance).

xxxix Derek K. Chu et al., Physical Distancing, Face Masks, and Eye Protection to Prevent Person-to-Person Transmission of SARS-CoV-2 and COVID-19: A Systematic Review and Meta-Analysis, The Lancet (June 1, 2020), available at https://doi.org/10.1016/S0140-6736(20)31142-9 (An “analysis of 172 studies confirms what scientists have said for months:
N95 and other respirator masks are far superior to surgical or cloth masks in protecting essential medical workers against the coronavirus.”); see also, Apoorva Mandavilli, Medical Workers Should Use Respirator Masks, Not Surgical Masks, N.Y. Times (June 1, 2020), https://www.nytimes.com/2020/06/01/health/masks-surgical-N95-coronavirus.html?referringSource=articleShare.


