July 31, 2020

The Honorable Kay Ivey
Governor of Alabama
600 Dexter Avenue
Montgomery, AL 36130

Dear Governor Ivey:

In honor of the Americans with Disabilities Act's (ADA) 30th anniversary and in light of the lessons learned from COVID-19, the ACLU of Alabama, Disability Rights and Resources, the Alabama Disabilities Advocacy Program, and Alabama Arise 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.

Since President George H.W. Bush signed this important civil rights law, people with disabilities have seen improved access to important programs and services, and many have successfully advocated for their rights. However, despite our success as a nation, people with disabilities still experience discrimination, especially those living in nursing homes and assisted living facilities.

In light of the current pandemic and the heightened risk that COVID-19 poses to institutionalized persons, 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. Your recent award of more than $18 million for testing in nursing homes is a critical and welcome step in the right direction,[1] but testing is not enough. To protect the health and well-being of institutionalized persons, it is critical that Alabama transition such individuals to the community. To that end, Alabama must also prioritize efforts to support healthcare workers, paid caregivers, and other essential employees who sustain people with disabilities who rely on home and community-based services.

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:
    - Prioritizing home and community-based services programs;
    - Assessing the status of residents in psychiatric hospitals;
    - Ensuring that advocacy organizations have access to facilities;
    - Supporting family members providing care.

- Protect residents in nursing homes and other large congregate facilities by:
    - Expanding data collection and transparency;
    - Conducting on-site monitoring for abuse and neglect.
- Support direct-service professionals and workers in congregate facilities by:
    - Providing personal protective equipment for workers;
    - 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. Recent reports indicate that more than 54,000 residents and workers have died as a result,[2] accounting for more than 40 percent of all deaths in the United States.[3] These statistics have shocked not only the healthcare community, but individuals and loved ones who live and work in these facilities. Alabama has not been spared, reporting more than 525 nursing home resident and staff COVID-19-attributed deaths as part of the federally mandated Centers for Medicare & Medicaid Services (CMS) data collection.[4] These deaths represent about half of the state's COVID-19-related deaths.[5] The state has reported more than 3,700 cases among long-term residents and 2,100 cases among staff.[6]

Segregated institutions are 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 care institutions (e.g., intermediate care facilities for people with developmental and intellectual disabilities, psychiatric hospitals, and large group homes) for which we lack sufficient data but where workers' and residents' risk of infection and death is 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 unworkable. Likewise, 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 the coronavirus and spreading it within their families and communities. This is 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 Alabama 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[7] and the heightened public health hazard that these congregate settings prove 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 care facilities for people with disabilities. We urge the Governor's Office to take the following steps:

1. Prioritize HCBS

Alabama should prioritize and expand Medicaid-funded Home and Community-Based Services (HCBS) programs to help people with disabilities and seniors live in their homes and communities rather than institutions. HCBS services are especially important during and after the pandemic, which has made the dangers of institutional life even more clear. Available data

indicates that the state spends 43 percent of its Medicaid Long-Term Services and Supports expenditures on HCBS, well below the national average.[8] HCBS 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 Alabama, have sought approvals from CMS for Section 1915(c) waiver Appendix K changes that have made it easier to access home and community-based services.

It is gratifying that Alabama's Appendix K waiver requests for HCBS would temporarily expand the settings where services may be provided, permit payment for services rendered by family caregivers or legally responsible relatives, and increase payment rates, among other requested provisions. The state should ensure that these allowances apply, where appropriate, to all the state's HCBS waiver programs. In particular, the state especially should ensure that payment is permitted for services rendered by family caregivers or legally responsible relatives across all waivers, and not just the ID/LAH waiver.[9] Other options, such as Community First Choice waivers, alternatives to hospitalization like "Hospital at Home" programs,[10] emergency personal assistance registries, and cohorting in alternative housing while transitioning to the community,[11] should also be used to supplement HCBS to reduce the institutional population.

To help people take advantage of these flexibilities, Alabama should also do more to promote this information in a plain-language, accessible, multi-lingual format to service providers, advocate organizations, families, and recipients of Medicaid long-term services and supports in any setting. The state should ensure that any multimedia is captioned and includes descriptions, and that agencies make American Sign Language interpreters and brailing services available.

Additionally, to assist Alabama in providing HCBS services, you should encourage the state's U.S. Senators to support Federal Medical Assistance Percentage (FMAP) increases in the next COVID-19 relief package that Congress likely will pass, including an HCBS-specific FMAP increase to defray the cost of these programs and avoid cuts in the future.[12]

2. <u>Assess the status of residents in psychiatric hospitals</u>

Aggressive action is necessary to reduce the number of people confined in psychiatric hospitals. Alabama should require psychiatric hospitals to certify and immediately report that they have individually assessed and re-evaluated all residents under their care to determine who can be discharged and what supports are required for them to live in the community. Officials should also ensure adequate supplies of PPE and verify that all staff members have adequate training.

The federal government's Substance Abuse and Mental Health Services Administration urges, 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)."[13] This standard must be applied in psychiatric centers until testing of patients and staff is widely done and safe isolation practices and social distancing protocols are in place.

Additionally, discharges should be accelerated. To decrease 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 greater 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. These efforts align with the ADA and the *Olmstead* decision to eliminate segregation and provide the most integrated setting based on an individual's needs.[14] Moreover, more families will offer to temporarily house and care for relatives being discharged from or not admitted to hospitals if 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 the state has taken or will take to address these concerns on behalf of people confined in psychiatric hospitals.

3. Ensure advocacy organizations have access to facilities to assess residents' ability to transition into the community

Many nursing homes have instituted lockdowns that prevent family members and advocacy groups from accessing residents. Although this measure may be necessary to limit virus transmission, Alabama should ensure access to congregate facilities for Independent Living Center staff, Aging and Disability Resource Center Ombudspeople, Protection and Advocacy staff, and others with expertise in transitioning people from institutions to the community. These individuals must be able to speak directly to all residents, either in person (with appropriate PPE provided) or via videoconference, to offer assistance for relocating and assessments of each person's desire to move to a safer location, either temporarily or permanently.[15]

4. Support family members providing care

Family caregivers play a crucial 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 family caregiver.[16] And more than 40 million family caregivers provide unpaid care each year.[17] But COVID-19 only exacerbates the economic, logistical, and health challenges caregivers face, especially as infections spread and new caregiving needs develop. Using emergency waivers or state plan authorities, state Medicaid agencies can permit family members or legally responsible individuals to be paid by relaxing background checks and other onboarding requirements for family members, as well as providing state plan or HCBS services.[18] Additionally, residents should be allowed to return to facilities if living conditions at home become unsafe or unmanageable.

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

5. Expand data collection and transparency

Only with improved reporting can those most affected by these issues make informed decisions about how to control, limit, and prevent COVID-19 infections and deaths. The recent CMS rule requiring collection and dissemination of nursing home information was a great step in the right direction.[19] But that mandate was incomplete. It only requires reporting from May onward and excludes the preceding months, even though the government already had declared that COVID-19 was a pandemic. The CMS data collection also does not mandate reporting on other types of congregate settings for people with disabilities. We need data about all deaths, for all reasons, and from all congregate facilities from the start of the calendar year.

Alabama's state-run data collection and transparency effort regarding congregate settings needs improvement. The COVID-19 Data and Surveillance Dashboard currently reports only total case counts for long-term care residents and employees.[20] It lacks facility-level data, data on the number of cases and deaths among residents and staff, or any type of demographic data. The state also fails to report any information about psychiatric hospitals and intermediate care facilities for individuals with intellectual disabilities (ICF-IIDs).

Across the nation, disability and worker rights groups have sounded the alarm about the lack of attention and resources devoted to residents and workers in these facilities.[21] We join them in expressing grave concern. Nationally, available data suggests that case fatality rates in ICF-IIDs, group homes, and psychiatric facilities are far higher than in the general population.[22] The approximately 500 people in Alabama's three public psychiatric hospitals,[23] 1,300 ICF-IID recipients living in settings for more than four people,[24] and residents of nearly 300 assisted living facilities (including specialty care)[25] are at heightened risk. The crisis requires more public data, transparency, and swift and concerted action by government leaders.

We therefore 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 comply with required data collection; require all congregate facilities for people with disabilities, *not just nursing homes*, to report to the Alabama Department of Public Health information about testing, PPE supplies, staffing levels, discharges and evictions, and each facility's positive cases and deaths of residents and workers. 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 each facility must be publicly available and posted on Alabama's COVID-19 Data and Surveillance Dashboard.

This data must include demographic breakdowns by race, ethnicity, sex, primary language, disability status, and age for infections, deaths, discharges, and evictions. COVID-19's effects land disproportionately on people with disabilities, Black and Latinx people, and women. All nursing home residents are people with disabilities, and nearly 70 percent are women.[26] As we detail below, the workforce caring for people in nursing homes and other congregate settings for people with disabilities disproportionately comprises women of color. More robust demographic reporting is needed to determine how COVID-19 affects these populations unequally. For example, recent reporting shows that, although about 14 percent of nursing home residents are Black and five percent are Latinx,[27] 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."[28] It would surprise no one if this disturbing situation exists in other congregate facilities.

6. <u>Conduct on-site monitoring for abuse and neglect</u>

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 state agencies like the Department of Senior Services to conduct routine, on-site monitoring of facilities, with appropriate PPE provided. Ensuring that advocacy organizations have access, as described above, will help uncover abuse and neglect when it occurs.

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

Alabama must do all in its power to meet the needs of essential workers who, at great risk to themselves, their families, and their communities, show 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 are women,[29] and 23 percent are immigrants.[30] Black women similarly are over-represented in the congregate care workforce.[31] Overall, the majority of women working as home health and personal care aides are women of color whose economic security is already precarious due to, in part, systemic racism that has long devalued caregiving[32] and fueled poverty-level wages.[33] 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.

7. Provide personal protective equipment for workers in all settings

Alabama must ensure that direct-service professionals providing home and community-based services and workers in congregate care facilities have the necessary supply of personal protective equipment, including gowns, N95 facemasks,[34] gloves, hand sanitizer, and eye protection.[35] The shortages nursing homes experience have been well documented.[36] Just two weeks ago, for instance, 59 Alabama nursing homes reported to CMS that they did not have a single week's supply of N95 masks. Thirty facilities were equipped with less than a one-week supply of surgical masks. And sixteen facilities reported lacking even a one-week supply of hand sanitizer.[37] The situation workers in other congregate care and home care settings face is dire, too,[38] and must be prioritized. Alabama, already facing a shortage of nursing staff and home care aides, cannot afford the risk of these essential workers contracting or spreading COVID-19 by going into these settings—particularly if they are providing care in multiple homes or settings. Seniors, people with disabilities, and workers will be at risk—*and will die*—without innovative and aggressive action to procure PPE.

8. Provide paid leave to workers in all settings

Alabama should provide at least two weeks of guaranteed paid sick leave to allow workers to care for themselves or family members, at the very least throughout the entirety of the public health emergency. COVID-19's spread highlights the health and economic consequences working people face 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.[39] Although 93 percent of the highest-wage workers have access to paid sick days, only 30 percent of the lowest-wage workers do. Those low-wage workers include the men and women who care for seniors and people with disabilities in facilities and in our communities. In Alabama, workers are especially vulnerable given state law that pre-empts local governments from enacting paid-leave policies.[40] Too many workers must choose risking either their health (and that of their families and communities) or the loss of a paycheck or job. No one should face this choice, let alone during an unprecedented public health emergency.

9. Increase worker pay and provide alternate housing

Alabama should increase workers' pay and offer alternative housing to workers, as other states have. Workers in COVID-positive facilities face the most pressing need, as they wish to avoid potentially exposing their families by returning home. As stated above, during this crisis our state

should compensate congregate care workers for dangerous workplace conditions by leveraging CMS waivers or state plan authorities to pay them hazard pay or overtime. We also should ensure that the temporary supplemental pay increases to direct-service professionals providing HCBS services apply to *all* state HCBS waiver programs. Further, Alabama should seek authorization for overtime pay by lifting caps on the number of hours workers may provide HCBS services. Protecting workers by providing PPE, paid sick leave, increased hazard pay, and alternative housing is smart for Alabama families, our communities, and our economy.

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Alabama and our nation face unprecedented challenges. In this moment, we are called to come together against not just a pandemic that has taken the lives of many, but also against long-entrenched biases that warehouse people with disabilities and systemic racism that has deeply wounded and killed more than we will ever know. In both instances, people with disabilities, Black people and other people of color have paid a steep price. But we can strike a blow against these scourges by implementing the policy proposals outlined in this letter. These recommendations will not only help to safeguard the lives of seniors and people with disabilities, but also greatly benefit the Black and Brown workers (and their families) who compose the majority of the workforce in congregate care facilities and HCBS programs.

We request a meeting with you and members of your administration to discuss these proposals so we may further our shared goal of protecting Alabama residents during the COVID-19 pandemic. Thank you for your consideration.

Sincerely,

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Dan Kessler
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Robyn Hyden
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cc: Dr. Scott Harris, State Health Officer
Stephanie Azar, Commissioner of the Alabama Medicaid Agency
Lynn T. Beshear, Commissioner, Alabama Department of Mental Health

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[1] Press Release, Office of the Alabama Governor, *Governor Ivey Awards $18.27 Million For Coronavirus Testing for Alabama Nursing Homes* (July 7, 2020), https://governor.alabama.gov/newsroom/2020/07/governor-ivey-awards-18-27-million-for-coronavirus-testing-for-alabama-nursing-homes/.

[2] *More than 43% of U.S. Corona Deaths Are Linked to Nursing Homes*, N.Y. Times (June 27, 2020), https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html. According to data published by the U.S. Department for Health and Human Services (HHS), at least 40,273 residents and staff of nursing homes in the United States have died of the coronavirus. *See* Ctrs. for Medicare & Medicaid Servs., *COVID-19 Nursing Home Data*, https://data.cms.gov/stories/s/COVID-19-Nursing-HomeData/bkwz-xpvg (data submitted as of week ending July 19, 2020). This figure that is almost certainly an undercount because under the reporting guidelines adopted by the Centers for Medicare and Medicaid Services (CMS), nursing homes are not required to report deaths or cases that occurred before May 8, despite the fact that the first reported nursing home outbreaks occurred in February.

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[4] Ctrs. for Medicare & Medicaid Servs., *COVID-19 Nursing Home Data*, https://data.cms.gov/stories/s/COVID-19-Nursing-HomeData/bkwz-xpvg (includes data submitted as of week ending July 19, 2020).

[5] Joshua Gauntt, *Long-term care residents make up nearly half of Alabama's COVID-19 death toll*, WBRC (June 19, 2020), https://www.wbrc.com/2020/06/20/long-term-care-residents-make-up-nearly-half-alabamas-covid-death-toll/.

[6] Ala. Dep't of Pub. Health, *Alabama's COVID-19 Data and Surveillance Dashboard*, https://alpublichealth.maps.arcgis.com/apps/opsdashboard/index.html#/6d2771faa9da4a2786a509d82c8cf0f7 (last visited July 30, 2020).

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[9] *Appendix K: Emergency Preparedness and Response and COVID-19 Addendum* (June 3, 2020), https://www.medicaid.gov/state-resource-center/downloads/al-0001-0391-combined-appendix-k-appvl.pdf (AL Home and Community-Based Waiver for Persons with Intellectual Disabilities (ID Waiver); AL HCBS Living at Home Waiver for Persons with ID); *Appendix K: Emergency Preparedness and Response and COVID-19 Addendum* (June 3, 2020), https://www.medicaid.gov/state-resource-center/downloads/al-0068-0878-0241-0407-combined-appendix-k-appvl.pdf (AL Home and Community-Based Waiver for the Elderly and Disabled; Alabama Community Transition; State of Alabama Independent Living (SAIL Waiver); Technology Assisted Waiver).

[10] Sarah Klein, Commonwealth Fund, *"Hospital at Home" Programs Improve Outcomes, Lower Costs But Face Resistance from Providers and Payers*, https://www.commonwealthfund.org/publications/newsletter-article/hospital-home-programs-improve-outcomes-lower-costs-face-resistance (last visited July 30, 2020).

[11] Silvia Yee, Disability Rights Edu. & Def. Fund, *DREDF Policy Recommendations for Reducing COVID-19 Nursing Home Deaths Through Innovative HCBS* (May 21, 2020) https://dredf.org/2020/06/04/dredf-policy-recommendations-for-reducing-covid-19-nursing-home-deaths-through-innovative-hcbs/.

[12] Letter from Disability and Aging Collaborative & Consortium for Citizens with Disabilities to Sens. Mitch McConnell & Charles Schumer (June 15, 2020), http://www.c-c-d.org/fichiers/National-and-State-Sign-on-COVID-19-Senate-Letter.pdf.

[13] Substance Abuse & Mental Health Servs. Admin., *Considerations for the Care and Treatment of Mental and Substance Use Disorders in the COVID-19 Epidemic* (May 7, 2020), https://www.samhsa.gov/sites/default/files/considerations-care-treatment-mental-substance-use-disorders-covid19.pdf.

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

[17] Nat'l Council on Aging, *Issue Brief: Support Family Caregivers and Home and Community-Based Services* (March 2016), https://d2mkcg26uvg1cz.cloudfront.net/wp-content/uploads/IB16-Family-Caregivers-and-HCBS-March.pdf.

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[22] *See, e.g.*, Joseph Shapiro, *COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities*, Nat'l Pub. Radio, (June 9, 2020), https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higheramong-those-with-intellectual-disabili; Ill. Dep't of Human Servs., *COVID-19 Confirmed Positive Cases* (July 30, 2020), https://www.dhs.state.il.us/page.aspx?item=123651.

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[30] Leah Zallman et al., *Care For America's Elderly And Disabled People Relies On Immigrant Labor*, 38 Health Affairs 919, 923 (June 2019), https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.05514.

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