



Alabama Disabilities Advocacy Program
Box 870395
Tuscaloosa, Alabama 35487
O (205) 348-4928
F (205) 348-3909
(800) 826-1675
adap@adap.ua.edu
<http://adap.ua.edu>

April 22, 2020

Via electronic mail

Governor Kay Ivey
Alabama State Capitol
600 Dexter Avenue
Montgomery, AL 36130

Re: Equitable, Life-Saving Care for People with Disabilities in Alabama during the COVID-19 Pandemic

Dear Governor Ivey:

Thank you for your leadership during this COVID-19 crisis.

We write on behalf of the Alabama Disabilities Advocacy Program (ADAP), which represents and serves the 17% of Alabamians who have disabilities, and organizations and agencies that have endorsed this letter.

We appreciate the swiftness with which the state of Alabama withdrew its prior Ventilator Treatment Guidance that excluded certain categories of people with disabilities from receiving life-saving ventilators should ventilator rationing become necessary in Alabama.

The Protection and Advocacy System for the State of Alabama

We have reviewed the State's [Crisis Standards of Care Guidelines \(CSC\)](#) dated February 20, 2020, which replaced the Ventilator Treatment Guidance, according to the Alabama Department of Public Health. Although we appreciate the general language in the CSC directing that the allocation of health care in a crisis must be provided in a non-discriminatory manner, there is no mention of ventilator triage in the CSC. Accordingly, we have several serious concerns that we believe must be addressed immediately, given that the COVID-19 virus could soon lead to the rationing of ventilators and other medical staff, equipment, and supplies.

We strongly urge that the Crisis Standards of Care specifically include the following to ensure that people with disabilities have equal access to life-saving treatment and that medical rationing is not based on disability or other categories prohibited by law. We also urge that the CSC be made mandatory, and not just advisory, for all healthcare facilities in the state.

1. Healthcare decisions will not be based upon race, gender, ethnicity, disability, age, sexual orientation, gender identity, immigration status, incarceration status, homelessness, socio-economic status, ability to pay, perceived quality of life, perceived social worth, or past or future use of resources.
2. There will be no exclusion criteria based on a particular disability. Decisions about how treatment should be allocated must be made based on individualized determinations, using current objective medical evidence. Individualized assessments must not be based on assumptions about a person's pre-existing condition or diagnosis, or the average life expectancy for people with such a pre-existing condition (i.e. HIV/AIDS, cancer, diabetes) or diagnosis.
3. Health care allocation decisions will not be based on age, "life years," life expectancy, or prognosis beyond short-term survival.
4. Decisions will not be made based on disabilities or underlying conditions unless:
 - (a) There is a clinically definitive terminal diagnosis and the individual meets hospice guidelines.
 - (b) There is a clinically definitive diagnosis that makes it highly unlikely that the person could survive the coronavirus.

5. Necessary accommodations will be provided to assist persons with communication, mobility, or other conditions to effectively participate in healthcare treatment decisions.
6. Reasonable modifications will be made to any standardized scoring instruments, like the SOFA or FAST, in order to accommodate specific disabilities or conditions.
7. Restoration criteria will only look at restoration to baseline. The fact that someone will need to use medical or social resources after discharge cannot be a factor in decision-making if the person needed those resources prior to the acute treatment.
8. No one who uses a ventilator on a regular basis (not related to COVID-19) will have their ventilator confiscated. Anyone already on a ventilator who is hospitalized for any other reason will be treated and the use of a ventilator will not reduce their triage score (someone already living on a ventilator may actually have greater survivability).

We look forward to working with your administration, the Alabama Department of Public Health, and other stakeholders to ensure that the State's guidance to healthcare personnel and facilities lives up to the State's commitment to protect ALL of Alabama's citizens.

Sincerely,

James Tucker, Director
Alabama Disabilities Advocacy Program

Cc: Dr. Scott Harris, State Health Officer, Alabama Department of Public Health
(via email)

Brian Hale, Esquire, General Counsel, Alabama Department of Public Health (via email)

David White, Senior Policy Advisor to Governor Kay Ivey (via email)

Endorsing Organizations:

The Alabama Conference of Executives of The Arc
Chris B. Stewart, President and CEO

The Arc of Alabama
Andrew Jackson Knight, Board President

The Arc of Baldwin County
Kathy Fleet, Executive Director

Accessible Alabama
Eric M. Peebles, PhD, CRC, President and Chief Executive Officer

Alabama Arise
Robyn Hyden, Executive Director

Alzheimer's of Central Alabama
Miller Piggott, Executive Director

Alabama Service Providers Association,
DeAnna Ferguson, President

The Disabilities Leadership Coalition of Alabama (DLCA)
Bill Fuller, Executive Director/Legislative Counsel

Disability Rights and Resources
Daniel G. Kessler, Executive Director

The Full Life Ahead Foundation
Judy Barclay, Acting Director

The Horizons School
Brian F. Geiger, EdD, FAAHE, CGSP, Executive Director

Mercy LIFE of Alabama
Donna Wilhelm, VP

People First of Alabama
Susan Ellis, Executive Director

Protection and Advocacy for Individuals with Developmental Disabilities (PADD)
Advisory Council
Joshua Echols, Chair

Protection and Advocacy for Individuals with Mental Illness (PAIMI) Advisory
Council
Amanda Deason, Chair

United Cerebral Palsy of Alabama
Deana Aumalis, President of the Alabama State Board

Volunteers of America Southeast
Wallace Davis, CEO/President