



Dignity. Respect. Advocacy.

Tom Masseau, Executive Director

April 2, 2020

The Honorable Asa Hutchinson
Governor of Arkansas
State Capitol Room 250
500 Woodlane Ave.
Little Rock, AR 72201

Dear Governor Hutchinson:

I would like to express my appreciation for your continued leadership during this crisis.

Disability Rights Arkansas, Inc. (DRA) is Arkansas's Protection & Advocacy system. We have been working cooperatively with our governmental partners during this difficult time to ensure that Arkansans with disabilities have equal access to all programs and services, including access to health care.

Over the preceding weeks, we have seen the current pandemic give rise to concerning circumstances in other states. Some states have adopted "crisis standards of care" (sometimes called "altered standards of care") to respond to the anticipated or realized shortage of medical resources, particularly ventilators. Other states have had ventilator allocation policies in place for some time and are now altering or considering altering such policies to meet the current crisis caused by the pandemic. It is our understanding that the Arkansas Department of Health (ADH) has not adopted such a plan in anticipation of the needs of the community during the current health crisis surrounding COVID-19. DRA, our federal partners, and our sister agencies in other states have identified serious gaps in the other states' policies which discriminate against people with preexisting disabilities and places them in potentially life-threatening positions. Before the crisis of medical resources overwhelms our state's hospitals, we respectfully request that your office empower ADH with the authority to issue crisis standards of care in a way that does not discriminate against individuals with disabilities.

Some of the policies we have seen, if implemented, will have the unintended consequence of disproportionately disqualifying many people with disabilities for ventilator access simply because they have underlying conditions that may intensify symptoms and slow recovery. We all need clear confirmation that people with disabilities and prior conditions will not be automatically or prematurely deprioritized for medical care. Hospitals and other medical facilities need to be provided clear guidance that such actions would be discriminatory, illegal and actionable.

In 1990, Congress acted to combat the widespread and persistent discrimination against people with disabilities in the United States with the implementation of the Americans with Disabilities Act (ADA).

Title II of the ADA prohibits state and local governments from discriminating against people with disabilities. Title III prohibits discrimination in places of public accommodation, such as hospitals, clinics, and doctor's offices. In addition, very recent direction from the United States Department of Health and Human Services Office of Civil Rights (OCR), in response to the rationing policy in Washington state, indicates that anticipated rationing must not discriminate against individuals with disabilities, as Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act are not suspended during this crisis.

One of the most important principles of disability discrimination law is that it prohibits covered entities from acting based on myths, stereotypes, and unfounded assumptions about people with disabilities.¹ Covered entities are required to make individualized determinations based on objective and current medical evidence.² It is of grave concern that rationing treatment on the basis of disability will leave large numbers of people without care simply by virtue of their status as an individual with a disability.

Applying the principles of the ADA, as well as other federal, state, and local laws, to the allocation of scarce medical treatment during a crisis requires the following be included in any guidance ADH provides to healthcare practitioners in order to avoid discriminatory outcomes:

1. Treatment allocation decisions must be made based on individualized determinations, using current objective medical evidence, and not based on generalized assumptions about a person's disability.
2. Treatment allocation decisions cannot be made based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living.
3. Treatment allocation decisions cannot be made based on the perception that a person with a disability has a lower prospect of survival. While the possibility of a person's survival may receive some consideration in allocation decisions, that consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities.
4. Treatment allocation decisions cannot be made based on the perception that a person's disability will require the use of greater treatment resources. Reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment.

Additionally, ADH must directly address the potential chilling impact that ventilator rationing will have on individuals with disabilities who utilize ventilators on a daily basis. When such actions have been anticipated in other states, our sister organizations received complaints from many chronic ventilator users who were afraid to seek medical help when they become ill because ventilator rationing may result in their every-day ventilators being re-allocated to other patients who are deemed a higher priority. These individuals expressed a genuine fear of forcible extubation, which would likely result in their deaths. We expect our clients would feel the same.

¹ *School Bd. Of Nassau County v. Arline*, 480 U.S. 273 (1987).

² *Bragdon v. Abbott*, 524 U.S. 624 (1998).

We have even heard of a case in a bordering state where an individual's personal ventilator was scheduled to be commandeered for the benefit of individuals currently requiring ventilation due to the pandemic. Proper procedures may require that an individual be removed from their personal ventilator to a hospital ventilator. However, a chronic ventilator user should never be removed from ventilation support for reasons of rationing. It is vital that explicit guidance from ADH to medical providers clearly set forth that such actions are never acceptable. A ventilator user can never be disconnected from ventilation support without a new device being readily available for their use.

We have seen California's Department of Human Service issue guidance that is similar to that provided by OCR, communicating that discrimination against people with disabilities in allocating scarce resources is not acceptable. Vermont, in consultation with our sister organization in that state, issued statewide policies that are mindful of the inherent bias that can occur when hospitals are left without uniform guidance. We expect Washington state to modify their policies in consultation with our sister organization this week. We are aware that our state medical university has individuals who specialize in medical humanities and bioethics. We strongly recommend that consultation with such specialists, individual stakeholders in the disability community, and our office, is paramount in ensuring that policies adopted do not run afoul of civil rights laws that protect individuals with disabilities.

We continue to be a partner with Arkansas during this unprecedented time. It is critical that ADH ensure that resource allocation procedures do not place people with disabilities at a disproportionate risk of death or other serious injury. We respectfully request that, before this crisis overwhelms our resources, that ADH issue guidance in a way that is cognizant of the guidance provided by OCR, and not discriminatory against individuals with disabilities. We stand ready to assist.

Respectfully,



Thomas Nichols
Director of Legal and Advocacy Services
Disability Rights Arkansas, Inc.

CC: Tom Masseur – Executive Director, Disability Rights Arkansas, Inc.