June 23, 2020

Hon. Douglas A. Ducey, Governor, State of Arizona
Dr. Cara Christ, Director, Arizona Department of Health Services
Jami Snyder, Director, Arizona Health Care Cost Containment System
Zane Garcia Ramadan, Acting Assistant Director, Arizona Department of Economic Security-Division of Developmental Disabilities

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

Dear Governor Ducey, Director Christ, Director Snyder, and Acting Assistant Director Garcia Ramadan:

We write on behalf of the tens of thousands of Arizonans who are persons with disabilities, persons with chronic health conditions, communities of color, and older individuals, and the organizations and agencies that have endorsed this letter.

Arizona is currently experiencing a precipitous rise in COVID-19 cases across the state, a situation that represents a life-threatening danger to tens of thousands of at-risk individuals. This situation has required utilization of the contingency level of the State's Crisis Standards of Care Guidelines (CSC) (3rd ed. 2020) and may well require implementation at the crisis level in all or portions of Arizona. Accordingly, we write regarding several concerns that we believe must be addressed immediately, given that the COVID-19 virus could soon lead to the rationing of medical staff, equipment, and supplies. While we all hope that Arizona healthcare providers are never faced with the types of decisions discussed here, clear guidance must be provided now.[1] This is entirely consistent with values expressed in the CSC, including:

[1] The CSC Code of Ethics for the State of Arizona recognizes a duty to plan ahead, to have clearly developed guidance for the crucial issues discussed here, and to "ensure that guidance on resource allocation is most effective, uniformly applied, and comprehensible, guidance will be as specific as possible." CSC, Appendix A.

- Consistency: Implement processes and procedures across the continuum of care, applying the same methods to achieve optimal community health.

- Fairness: Respect and recognize the dignity of all populations when providing healthcare across the continuum of care.

CSC at 4. Further, the CSC acknowledges that "Policies and Guidance should account for and pay particular attention to the needs of the most at-risk and marginalized people . . . to support equitable and just distribution of scarce resources." This principle is particularly relevant to persons with disabilities, communities of color, and older adults – all of whom are at high risk of infection and death from COVID-19, and all of whom have been disproportionately impacted by the pandemic. These groups have all experienced significant discrimination and still do. Just as clear legal protections have been required to protect these groups in the past, equally clear and specific protections are needed in Arizona's CSC now. Ensuring equal access to limited, life-saving resources, non-discriminatory decisions concerning resource allocation, and implementation of the CSC requires your urgent attention.

The Arizona Center for Disability Law (ACDL) previously wrote to the Arizona Department of Health Services (ADHS) and explained in detail the federal statutes that prohibit discrimination against people with disabilities, and how those statutes require protections in the CSC for people with disabilities. (*See* Letter from ACDL, dated April 10, 2020, which is attached for your convenience). ACDL urged that the then-current version of the CSC be modified to incorporate explicit non-discrimination provisions concerning allocation of resources, reasonable accommodations for persons with disabilities, and necessary modifications to generally applicable policies. Unfortunately, the recently revised CSC did not incorporate any such provisions, nor did ACDL receive a response to its letter.

We have reviewed the State's revised CSC document thoroughly. 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. However, there are many important issues not addressed in the CSC, including guidelines and criteria for allocating life-saving resources, the processes for rendering and appealing these decisions, the provision of reasonable accommodations to address the needs of persons with disabilities, and methods to address the unique health inequities affecting communities of color and older adults. Instead, all of these critical issues are left to the discretion of the State Disaster Medical Advisory Committee (SDMAC), which is charged with developing guidance on these issues within the general topics of:

- Triage for emergency medical services (EMS);

- Primary, secondary, and tertiary triage for healthcare facilities;

- Priorities for medical resources including space, staff, and supplies.

See CSC at 2, 16, 17, and 80.

While the SDMAC has provided *pre-hospital* triage guidance for COVID-19, it has not provided specific guidance regarding triage for hospitals and other healthcare facilities, or priorities for medical resources.[2] Additionally, the provisions in the CSC addressing triage and allocation of scarce resources could be interpreted in a manner that results in discrimination against at-risk populations, and especially persons with disabilities, older adults, and communities of color. *See* CSC at 38-39 (resources including ventilators, oxygen delivery devices, and medications should be allocated to patients whose "need is greater" or whose prognoses are more likely to result in "a positive outcome."). In fact, these criteria will severely disadvantage these populations precisely because of their pre-existing conditions, disabilities, or age-related illnesses, in direct contravention to the protections afforded by several anti-discrimination laws.

It is with these thoughts and principles in mind that we write now to assure the protection of individuals with disabilities, persons with co-morbidities, communities of color, and all older Arizonans.

We strongly urge that the Crisis Standards of Care specifically include the following to ensure that all citizens have equal access to life-saving treatment and that medical rationing is not based on disability, age, race, ethnicity, or other categories prohibited by law. It is especially important that there is a revised version of the CSC that is applicable to all hospitals and healthcare facilities, rather than left to the discretion of the SDMAC, or worse, the discretion of individual healthcare facilities or providers in the state.

1. The current CSC Code of Ethics, Section 4.2 provides:

> Public health responses and allocation of scarce resources (such as vaccines, ventilators, or evacuation assistance) may not be based on factors unrelated to health status and emergency response needs. Impermissible factors include, but are not limited to: race, gender, ethnicity, religion, social status, location, education, income, ability to pay, disability unrelated to prognosis, immigration status, or sexual orientation. *See* CSC at 92.

   In addition to being made mandatory in the CSC, this provision should clearly prohibit making healthcare decisions based on disability, perceived quality of life, perceived social worth, perceived potential for long-term survival, a person's need for disability-related accommodations, or past or future use of resources. Importantly, the words "disability unrelated to prognosis" should be deleted, since this broad concept encompasses a wide range of disabilities that are unrelated to immediate survival from COVID-19.

2. There should not be any exclusionary criteria, whether explicit or implicit, based on a particular disability, co-morbid condition, age, or any other factor unrelated to immediate survivability and successful discharge from a hospital. Health care

[2] The SDMAC pre-hospital guidance can be found at: https://www.azdhs.gov/documents/preparedness/epidemiology-disease-control/infectious-disease-epidemiology/novel-coronavirus/sdmac/sdmac-guidance-pre-hospital-triage.pdf.

providers are prohibited from making treatment decisions that discriminate against people with disabilities, older adults, and people and communities of color. 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]

3. Health care allocation decisions should not be based on age, "life years," life expectancy, or prognosis beyond immediate short-term survival. The recent addendum to the CSC places individuals who are likely to survive less than one (1) year at a lower priority for access to health care resources, which is a consideration of long-term survival rather than short-term survival. Such a consideration will disproportionately de-prioritize people with disabilities from receiving critical care. The CSC should explicitly state its sole decision-making criterion is saving lives in the immediate short-term, without discrimination.

4. Health care allocation decisions should not be made based on disabilities, age, or underlying conditions unless:
   (a) There is a clinically-definitive terminal diagnosis that makes mortality imminent and the individual meets hospice guidelines.
   (b) There is a clinically-definitive prognosis that makes it highly unlikely that the person could survive the coronavirus in the immediate short-term.

5. Necessary accommodations and/or auxiliary aids and services should be provided to assist persons with communication, mobility, or other conditions to effectively participate in healthcare treatment decisions. Such accommodations may include altering visitation rules for patients with cognitive disabilities, or provision of interpreters to overcome language barriers. (*See* CSC at 84, which recognizes the need for accommodation consistent with disability protection laws, but provides no guidance or directives for hospitals on this issue.)

6. Reasonable modifications will be made to any standardized scoring instruments, like the Sequential Organ Failure Assessment (SOFA), in order to accommodate specific disabilities or underlying conditions and reflect an objective assessment of immediate short-term survival.

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[3] On March 28, 2020, the U.S. Department of Health and Human Services Office for Civil Rights (OCR) issued a Bulletin regarding nondiscrimination laws as they pertain to the response to COVID-19. In this Bulletin, OCR states that civil rights laws, including Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act remain in effect during the COVID-19 public health emergency. The Bulletin continues, "persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age." OCR also states that treatment decisions should be based on individualized assessments of patients and the best available objective medical evidence. *See* BULLETIN: Civil Rights, HIPAA and the Coronavirus Disease 2019 (COVID-19), March 28, 2020. https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf

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 removed or reallocated to other persons. 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).

Given the COVID-19 surge in our state, the above-noted deficiencies and omissions in the current CSC, and urgency of addressing these issues, we believe that the Arizona Department of Health Services needs to immediately revisit the CSC and incorporate provisions addressing each of the issues noted above. To the extent the work of other States is useful, we are enclosing the recently-revised CSC from Delaware, which does address these issues in an appropriate manner.

We request a meeting with the relevant state officials to discuss how to promptly address these issues and to revise the CSC. We look forward to working with your administration, the Arizona Department of Health Services, 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 Arizona's residents.

Sincerely,

Phil Pangrazio, President & CEO
Ablity360

Amanda Parris, Policy Counsel
American Civil Liberties Union of Arizona

Jon Meyers, Executive Director
The Arc of Arizona

John C. McDonald, Chief Executive Officer
Arizona Alliance for Community Health Centers

Wendy Shaw, Chair
Arizona Association of Providers for People with Disabilities

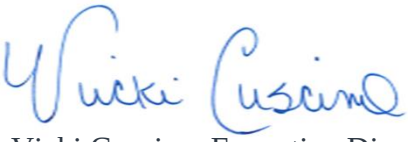
Connie Robinson, Chair
Arizona Center for African Amerian Resources

Asim Dietrich, Staff Attorney
Arizona Center for Disability Law

Danny Adelman, Executive Director
Arizona Center for Law in the Public Interest

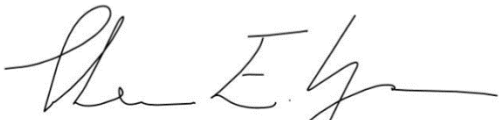
Will Humble, Executive Director
Arizona Public Health Association

Sarah Kader, Director of Operations
Arizona Statewide Independent Living Council

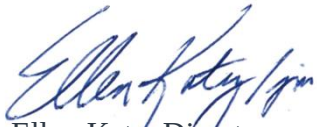


Vicki Cuscino, Executive Director
DIRECT Center for Independence

Diane Yazzie-Devine, President & CEO
Native American Connections



Therese Yanan, Executive Director
Native American Disability Law Center



Ellen Katz, Director
William E. Morris Institute for Justice