

NOTE: Copy updated to include Easterseals in the endorsement of the effort to have the Arizona Dept. of Health and Human Services upgrade the state's Crisis Standards of Care.

PRESS RELEASE FOR IMMEDIATE RELEASE July 21, 2020

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## As the spread of COVID-19 worsens, 'Crisis Standards of Care' nationwide must consider the civil and human rights of people with disabilities and other vulnerable populations

• National advocates for people with disabilities support civil rights complaint filed by Arizona organizations

WASHINGTON, D.C. – An ad hoc coalition of advocacy groups from across the country is urging state and county health authorities to ensure that Crisis Standards of Care guidelines do not lead to the discriminatory denial of life-saving healthcare for people with disabilities during the COVID-19 pandemic.

The organizations supporting this position include: <u>United Cerebral</u> <u>Palsy</u>, <u>Easterseals</u>, <u>ACCSES</u>, <u>TASH</u>, and the Arizona-based groups <u>Raising Special Kids</u>, <u>First</u> <u>Place AZ</u>, and <u>United Cerebral Palsy of Central Arizona</u>.

The Arizona Department of Health Services (ADHS) last month authorized hospitals in the state to activate <u>Crisis Standards of Care guidelines</u> and a COVID-19 Addendum to the guidelines to permit the allocation of hospital care and resources based on a set of predetermined criteria, measured by a point system, that ranks a patient's likelihood of

survival.

This was done because of fears that treatment facilities could be overrun by patients sickened by COVID-19. Activating the Crisis Standards of Care also provides liability and malpractice protection for doctors and other medical personnel, ADHS Director Dr. Cara Christ told reporters at a Phoenix press conference in June.

As a leading voice on disability rights, United Cerebral Palsy and its national and Arizona partners are supporting an effort initiated in recent weeks by several Arizona advocacy groups to convince ADHS and Arizona Gov. Doug Ducey to modify the Crisis Standards of Care so they can be administered in a nondiscriminatory manner.

While state health departments nationwide have CSC guidelines, <u>Arizona is believed to be the</u> <u>first state in the country</u> that has granted hospitals the authority to implement them.

"The global pandemic has created unprecedented challenges for our healthcare community, but we cannot allow the magnitude of the health crisis created by COVID-19 infringe upon the civil and human rights of the most vulnerable among us," said United Cerebral Palsy President and CEO Armando Contreras. "As doctors, nurses and other healthcare workers struggle to meet the challenges of the pandemic, every effort must be made to protect the rights of people with disabilities, the elderly, and other vulnerable groups."

Arizona-based advocates for people with disabilities, the elderly, and other vulnerable populations have asked Christ and Gov. Doug Ducey in written correspondence to modify the state's existing CSC guidelines to protect against discriminatory practices that may violate the civil rights of COVID-19 patients. The same request was made to Arizona Health Care Cost Containment System Director Jami Snyder and Division of Developmental Disabilities Acting Assistant Director Zane Garcia Ramadan.

Among the groups pressing for these changes to the CSC guidelines are the Arizona Center for Disability Law (<u>ACDL</u>), The Arc of Arizona, Arizona Association of Providers for People with Disabilities, Arizona Center for Law in the Public Interest, ACLU of Arizona, and several other civil and human rights groups.

Representatives of these groups have also met personally with Dr. Christ to outline their concerns. According to ACDL staff attorney Asim Dietrich, state officials have not responded to the group's requests.

As a result, ACDL filed a formal complaint on Friday with the U.S. Department of Health and Human Services <u>Office of Civil Rights</u> to force a review of Arizona's CSC guidelines.

"In recent weeks, nearly a dozen similar plans in states across the U.S. have been significantly revised to ensure protections for vulnerable populations such as those identified in this letter to the State of Arizona," according to a statement issued by the Arizona Center for Disability Law.

For example, both California and Delaware have updated their Crisis Standards of Care to prevent discriminatory healthcare decisions.

Given the ongoing spike in COVID-19 cases nationwide and predictions by leading epidemiologists that the spread of the virus could worsen in the fall, United Cerebral Palsy strongly urges state and federal health authorities to issue explicitly nondiscriminatory CSC guidelines on how to treat people with disabilities.

<u>As noted in the ACDL statement</u>, "Persons with disabilities, communities of color, and older adults – all of whom are at high risk of infection and death from COVID-19, all of whom have historically experienced broad discrimination, and all of whom have been disproportionately impacted by the pandemic – need clear and specific protections to be listed."

"As the pandemic continues," Contreras added, "it is critically important that non-COVID health care services continue to be provided to people with disabilities and other vulnerable populations."

UCP and its partners support the following requests by the ACDL and its Arizona partners to immediately revise the state's CSC guidelines to:

- Prohibit making healthcare decisions based on assumptions about long-term life expectancy, instead only considering short-term survival and imminence of mortality
- Provide necessary accommodations and/or auxiliary aids and services to assist persons with communication, mobility, or other conditions to effectively participate in healthcare treatment decisions.
- Require modifications to be made to any standardized scoring instruments in order to accommodate specific disabilities or underlying conditions and reflect an objective assessment of immediate short-term survival.
- Prohibit decision-making based on assumptions about perceived health or pre-existing conditions
- Prohibit the past or possible future use of medical or social resources as a factor in decision-making if the person needed those resources prior to treatment.
- Provide notice and appeal rights for triage decisions
- Provide reasonable modifications to visitation restrictions when necessary for a person with a disability to access a support person or family member

## About United Cerebral Palsy (UCP)

United Cerebral Palsy has proudly served the disability community for over 70 years. The network has 63 affiliates across the United States and Canada that provide direct program services to more than 155,000 individuals and families. UCP is dedicated to ensuring that people with disabilities live a life without limits.