



July 17, 2020

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue SW
Washington, DC 20201

Re: Complaint of Donna Jeffrey, Joseph Zachary, Arizona Center for Disability Law, The Arc of Arizona, Arizona Center for Law in the Public Interest, and Native American Disability Law Center, Against the Arizona Department of Health Services

Dear Mr. Severino:

We are submitting this Complaint about illegal discrimination on the basis of disability, age, and race, that is placing people in those protected classes in Arizona at risk of substantial and imminent harm during the COVID-19 pandemic.

This Complaint addresses the Arizona Crisis Standards of Care (CSC) (3rd ed. 2020)¹ and the June 12, 2020, COVID-19 Addendum: Allocation of Scarce Resources in Acute Care Facilities (Addendum),² which are currently being implemented in Arizona, and which discriminate against people with disabilities, older Arizonans, and individuals from communities of color, in violation of federal civil rights laws, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), Age Discrimination Act of 1975 (the Age Act), Title VI of the Civil Rights Act of 1964 (Title VI), and Section 1557 of the Affordable Care Act (ACA). Arizona's CSC and Addendum include considerations and bias that will operate to deny life-saving care to people with disabilities, older Arizonans, and individuals from communities of color.

As will be explained in detail below, the CSC and Addendum illegally discriminate because:

- They allow long-term life expectancy and the opportunity to experience “life stages” to be used as factors in the allocation of scarce medical resources. The use of these factors discriminates against older adults and many people with disabilities. They also are likely to lead to discrimination against individuals from communities of color.

¹ Arizona Crisis Standards of Care (CSC) (3rd ed. 2020)
<https://www.azdhs.gov/documents/preparedness/emergency-preparedness/response-plans/azcsc-plan.pdf>.

² COVID-19 Addendum: Allocation of Scarce Resources in Acute Care Facilities
<https://www.azdhs.gov/documents/preparedness/epidemiology-disease-control/infectious-disease-epidemiology/novel-coronavirus/sdmac/covid-19-Addendum.pdf>.

- They fail to prohibit illegal decision-making considerations such as intensity and duration of need and existence of pre-existing conditions in allocating life-saving treatment resources.
- They fail to require reasonable modifications to the primary scoring instruments used in the triage process when necessary to accommodate an individual's disability. Reasonable accommodations are necessary to ensure that people with disabilities are evaluated based on their actual mortality risk, not disability-related characteristics unrelated to their likelihood of survival.
- They fail to require reasonable modifications to hospital communication and strict no-visitation policies, which are necessary to accommodate the needs of many individuals with disabilities.

The COVID-19 situation in Arizona is currently dire. Arizona was recently ranked at the top of the list for the highest number of confirmed COVID-19 cases per million residents *in the world* within the first week of July.³ COVID-19 continues to spread at unprecedented rates in Arizona, putting enormous strain on our medical system and placing residents at risk of discrimination as the CSC and Addendum are implemented as written. The Arizona Department of Health Services (ADHS) recently revised the CSC, and adopted and published the Addendum developed based on a proposal by a coalition of healthcare providers, noting that it “specifies statewide triage protocols for acute care facilities during the COVID-19 pandemic.”⁴ On June 29, 2020, ADHS activated the CSC, authorizing healthcare systems and hospitals to implement the CSC and the Addendum.⁵ Many healthcare systems and hospitals in Arizona have activated the CSC and Addendum and are prepared to implement its rationing and triage protocols if, or when, resources such as ICU or ventilator capacity are insufficient. These protocols offer the potential for systemic and systematic discrimination against vulnerable populations across Arizona in the provision of healthcare, including those represented by the individuals and organizations that are party to this Complaint.

The Arizona CSC and Addendum place many people with disabilities, older adults, and people from communities of color, at significant risk of harm, and possibly death. Complainants' constituents and members include people who have or may be

³ *Arizona is #1; Bahrain is #4*, New York Times, July 8, 2020, <https://www.nytimes.com/2020/07/08/briefing/arizona-mary-trump-facebook-your-wednesday-briefing.html?searchResultPosition=5>; see also COVID-19 Case Rate in the U.S. Reported to the CDC, by State/Territory (cases per 100,000), <https://www.cdc.gov/covid-data-tracker/#estimate-icu-beds>.

⁴ Addendum at 1.

⁵ *As COVID-19 worsens, AZ is the first state to enact 'crisis care' standards*, AZ Mirror, July 3, 2020, <https://www.azmirror.com/2020/07/03/as-covid-19-worsens-az-is-the-first-state-to-enact-crisis-care-standards/>.

erroneously perceived as having a shorter life expectancy based on disability, which under the current CSC and Addendum could be used to justify denying, withdrawing, or de-prioritizing their medical care in times of crisis and medical resource scarcity. The same is true of older adults, who may be denied care based on the “life stages” factor. This disability and age discrimination is permitted despite the established inability of providers to accurately predict long-term life expectancy. Although the Addendum states that individuals will not be categorically denied care based upon quality-of-life assumptions, other provisions within the Addendum such as considerations of long-term life expectancy, or the ability to experience life stages, and future resource intensity implicitly allow quality-of-life assumptions to be a factor in medical decisions. Moreover, many people with disabilities will receive higher scores on assessment tools simply because of the impact of their disabilities on the test results. The failure to make reasonable modifications to assessment instruments, to provide for effective methods of communication, and to modify visitor policies explicitly discriminate against people with disabilities. Complainants’ constituents and members deserve equal access to medical care and should not be denied care based on their disability and need for reasonable modifications, their age and cycle of life or prognosis for long-term life expectancy, or their race or other protected status.

Similarly, although the CSC and Addendum contain general prohibitions against using race or age as considerations to justify de-prioritizing care, the Addendum contains several provisions that could – and likely will – lead to discrimination against people with disabilities, older Arizonans, and individuals from communities of color. For example, the use of factors such as an evaluation of 1-5-year mortality will discriminate against older Arizonans and many people with disabilities. It also could easily lead to discrimination against communities of color, because – for example – African Americans statistically have a shorter life expectancy than Caucasians. Further, accurate predictions of life expectancy of up to 5 years are extremely difficult under normal circumstances, and in the context of a pandemic where expedited triage decision-making will occur, it is nearly impossible.

Given the current crisis in Arizona, and the real and present danger that the CSC and Addendum will be invoked imminently to ration healthcare, it is essential that the Office for Civil Rights (OCR) take immediate action to address this discrimination and ensure that the Arizona CSC and Addendum are amended to prevent discriminatory, life-or-death decisions concerning the allocation of healthcare in Arizona from occurring.

Complainants

Donna Jeffrey and Joseph Zachary as individuals, and The Arizona Center for Disability Law (ACDL), The Arc of Arizona, The Arizona Center for Law in the Public Interest, and The Native American Disability Law Center (collectively, Complainants), file this Complaint on behalf of their constituents and members, Arizonans with disabilities, older Arizonans, and communities of color, all of whom will likely face discrimination and

potential negative health outcomes, including death, as a result of application of the discriminatory CSC and Addendum.

Individual Complainants

Donna Jeffrey is a 47-year-old resident of Mesa, Arizona, with muscular dystrophy. When she was originally diagnosed with muscular dystrophy at age seven, she was told she would not live past age 21. Ms. Jeffrey has been living an independent life since age 18, including attending college and working in quality assurance. She currently manages the household that she shares with her elderly mother. She is a full-time electric wheelchair and ventilator user, and requires the assistance of disability service providers to perform activities of daily living. Ms. Jeffrey is concerned that if she were to be hospitalized during the COVID-19 pandemic, she may be denied lifesaving medical care because of her disability due to the standards included in the CSC and Addendum. The CSC and Addendum are likely to discriminate against Ms. Jeffrey and deny her lifesaving care based upon her disability. Specifically, the CSC authorizes hospitals to consider long-term life expectancy, and to use assessment tools like the Sequential Organ Failure Assessment (SOFA) without allowing any reasonable modifications to account for her disabilities. The use of an unmodified SOFA on Ms. Jeffrey would be discriminatory as she has limitations on purposeful movement that would affect the neurological screen. This failure to allow reasonable modifications to the SOFA and other evaluation instruments could well result in the denial of lifesaving care to Ms. Jeffrey. Moreover, although doctors are unable to predict long-term life expectancy with any accuracy, the CSC authorizes hospitals to assign negative points to an individual based on an assessment that the person is unlikely to survive five years past hospitalization. A doctor could assign these points to Ms. Jeffrey based on her age and disability. Further, unless Ms. Jeffrey's predictable need for ongoing social or medical resources is prohibited as a consideration, Ms. Jeffrey is concerned that she may be denied lifesaving care because she requires long-term ventilator use and disability service provider assistance for activities of daily living due to her underlying disability. She would also face unequal medical care if she were to be hospitalized and the hospital were to not grant a modification to allow her to be accompanied by a disability service provider who could provide her with the extra assistance she needs as a person with a disability, which would not be appropriately provided by medical staff overwhelmed by demands of other critically ill patients.

Joseph "Joey" Zachary is a 27-year-old man with cerebral palsy. He was diagnosed with cerebral palsy when he was approximately 18 months old. At that time, doctors expected Joey to live for approximately two weeks. Joey has not only continued to live but has flourished. He is non-verbal, uses a wheelchair, and has a full life with his loving family. He enjoys music, arts and crafts, the outdoors, and animals, and he is an integral part of his family's daily life. Due to his disability, Joey requires full assistance with all of his activities of daily living. The CSC and Addendum discriminate against Joey who is non-verbal, cannot make purposeful movement, has a tracheostomy, a feeding tube, a suction

machine, and a wheelchair. Sharon, Joey's mother and guardian, is concerned that in the event Joey is hospitalized during this pandemic, a requirement to consider long-term life expectancy, and allowing assessment instruments like the SOFA to be used without reasonable modifications to account for underlying disabilities will result in discrimination and could well result in the denial of lifesaving care. Sharon is also concerned that Joey could be denied lifesaving care because ADHS currently allows healthcare providers to consider pre-existing diagnoses, resource intensity, and duration of need when making medical decisions. If Joey's ongoing need for social or medical resources is considered, he may also be denied lifesaving care because he is enrolled in the State Medicaid program. Lastly, if Joey is hospitalized, his life would be in jeopardy if visitation policies were not modified to allow Sharon or caregivers to visit and provide 1-on-1 support for him because they have specialized knowledge about his disability related healthcare needs.

Organizational Complainants

ACDL is a non-profit law firm and the designated Protection and Advocacy system for Arizona, serving people with mental, physical, or developmental disabilities pursuant to the federal protection and advocacy acts.⁶ As Arizona's Protection & Advocacy system, ACDL is specifically authorized to pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of individuals with disabilities.⁷ Pursuant to this authority, ACDL brings claims on behalf of individuals with disabilities who are currently seeking or may seek acute medical care in Arizona during the COVID-19 pandemic.

The Arc of Arizona promotes and protects the human rights of people with intellectual and developmental disabilities through public policy advocacy, community organizing, and education and outreach, and actively supports their full inclusion and participation in the community throughout their lifetimes.

The Arizona Center for Law in the Public Interest (Center) is a nonprofit law firm dedicated to defending the civil and legal rights of Arizonans, pursuing cases with enduring social, public health, and environmental impacts statewide. The Center regularly advocates for the rights of people with disabilities, older adults, and communities of color, and is authorized to bring legal, administrative, and other claims on behalf of the communities it serves.

The Native American Disability Law Center (Law Center) is designated by the Navajo Nation and Hopi Governments as the protection and advocacy organization for their communities. The Law Center is part of the federal protection and advocacy system and

⁶ 42 U.S.C. § 10801, *et seq.* (Protection and Advocacy for Individuals with Mental Illness Act); 29 U.S.C. § 794e (Protection and Advocacy for Individual Rights Act); 42 U.S.C. § 15041 *et seq.* (Developmental Disabilities Assistance and Bill of Rights Act).

⁷ See 42 U.S.C. § 15043(a)(2)(A)(i); 42 U.S.C. § 10805(1)(B); 29 U.S.C. § 794e(f)(3).

was created to address the unique legal issues facing Native Americans with disabilities. Located in the Four Corners Region of the Southwest, where Arizona, New Mexico, Colorado and Utah meet, the Law Center provides legal advocacy and training to protect the civil rights of Native Americans with disabilities at the tribal, state, and federal level. The Law Center focuses on providing support and services that enable Native American with disabilities to live as independently as possible in their own communities surrounded by people who share their culture, language, and values. With the majority of the Law Center's service region located in northern Arizona, the Law Center is very concerned about the medical care provided to Native Americans with disabilities from across northern Arizona. This issue becomes more essential when many are transferred from the Navajo Nation and Hopi communities to the southern urban areas. These transfers prevent families from being present and advocating for their family.

The Complainants request that OCR investigate and issue findings and guidance in this matter on an expedited basis due to the critical status of the COVID-19 pandemic in Arizona. This guidance is necessary to ensure that hospitals and providers do not make treatment decisions that violate the nondiscrimination mandates of the ADA, Section 504, the Age Act, Title VI, and Section 1557 of the ACA.

Federal Law Prohibits Discrimination on the Basis of Disability, Age, Race, and National Origin in the Provision of Medical Treatment

Several federal laws prohibit discrimination against people on the basis of disability, age, race, color, and national origin, by public entities.⁸ Based on the information currently available to Complainants, under the existing CSC and Addendum, Arizona is already applying standards that would deny lifesaving medical treatment to individuals based on their underlying disabilities, age, and race. Discriminatory decisions such as these would lead to people being denied life-saving care and even dying as a result of their disability, age, race, ethnicity, or national origin in violation of federal law.

Legal Requirements

The Americans with Disabilities Act (ADA) was passed in 1990 to combat the widespread discrimination against people with disabilities in American society. Specifically, the ADA states that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem," and

⁸ See *e.g.*, Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794(a); Section 1557 of the Affordable Care Act; and Age Discrimination Act, incorporated by Section 1557 of the ACA (prohibiting discrimination on the basis of age in programs or activities that receive federal financial assistance), 42 U.S.C. § 18116, 42 U.S.C. §§ 6101-6107, 34 C.F.R. § 110.10(a).

that discrimination against individuals with disabilities persists in critical areas, including in health services and access to public services.⁹

The overarching purpose of the ADA is to “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities,” and to “provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities.”¹⁰

Title II of the ADA prohibits public entities, such as state and local governments, from discriminating against people with disabilities. Specifically, “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”¹¹ ADHS is a public entity within the meaning of Title II, as it is an agency of the State of Arizona,¹² and provides “services, programs, [and] activities” related to health services in Arizona.¹³

Arizona’s CSC and Addendum violate Title II of the ADA and its implementing regulations by authorizing or failing to forbid actions that:

- Deny a qualified individual with a disability the benefits of the services, programs, or activities of a public entity because of the individual’s disability.¹⁴
- “Aid or perpetuate discrimination against a qualified individual with a disability by providing significant assistance to an agency, organization, or person that discriminates on the basis of disability in providing any aid, benefit, or service to beneficiaries of the public entity’s program.”¹⁵
- “[L]imit a qualified individual with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving the aid, benefit, or service.”¹⁶
- “[D]eny a qualified individual with a disability the opportunity to participate in services, programs, or activities that are not separate or different, despite the existence of permissibly separate or different programs or activities.”¹⁷

⁹ 42 U.S.C. §§ 12101(2), (3).

¹⁰ *Id.* at §§ 12101(b)(1), (2).

¹¹ *Id.* at § 12132.

¹² *Id.* at § 12131(1).

¹³ 28 C.F.R. § 35.130.

¹⁴ 42 U.S.C. § 12132.

¹⁵ 28 C.F.R. § 35.130(b)(1)(v).

¹⁶ 28 C.F.R. § 35.130(b)(1)(vii).

¹⁷ 28 C.F.R. § 35.130(b)(2).

- “Directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities; or (iii) That perpetuate the discrimination of another public entity if both public entities are subject to common administrative control or are agencies of the same State.”¹⁸
- Fail to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.”¹⁹
- “Impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.”²⁰

Section 504 of the Rehabilitation Act of 1973 (Section 504) also prohibits discrimination against people with disabilities by entities that receive federal financial assistance. ADHS is a recipient of federal financial assistance, and is therefore required to comply with the nondiscrimination mandate of Section 504.²¹ Section 504 provides, in pertinent part that “no otherwise qualified individual with a disability in the United States... shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”²² ADHS also provides a “program or activity” where “program or activity” is described as “all operations of a department, agency, special purpose district or other instrumentality of a State or of a local government.”²³

Arizona’s CSC and Addendum violate Section 504 and its implementing regulations by authorizing or failing to forbid actions that:

¹⁸ 28 C.F.R. § 35.130(b)(3).

¹⁹ 28 C.F.R. § 35.130(b)(7).

²⁰ 28 C.F.R. § 35.130(b)(8).

²¹ Further, as places of public accommodation and as recipients of federal funds, including Medicaid and Medicare reimbursement, Arizona hospitals – which will be implementing the CSC and Addendum – are subject to the non-discrimination provisions of the Rehabilitation Act and the other federal statutes discussed throughout this Complaint.

²² 29 U.S.C. § 794(a).

²³ 29 U.S.C. § 794(b)(1)(A).

- Exclude from participation in, deny the benefits of, or otherwise subject individuals to discrimination on the basis of disability.²⁴
- Deny qualified persons with a disability the opportunity to participate in or benefit from the aid, benefit, or service.²⁵
- Afford qualified persons with a disability an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded to others.²⁶
- Limit individuals with a disability in the enjoyment of rights, privileges, advantages and opportunities enjoyed by others receiving an aid, benefit, or service.²⁷
- Use criteria or methods of administration that have the effect of subjecting qualified persons to discrimination on the basis of disability, or that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of a program or activity with respect to persons with disabilities.²⁸
- Fail to make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities.²⁹

The Age Discrimination Act of 1975 (Age Act) prohibits discrimination based on age by health care providers receiving federal funding. The text establishes that “no person... shall, on the basis of age, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any program or activity receiving Federal financial assistance.”³⁰ OCR applied the Age Act to resolve complaints alleging discriminatory criteria in crisis standards of care in other states.³¹

Arizona’s CSC and Addendum violate the Age Act and its implementing regulations by authorizing actions that:

²⁴ 29 U.S.C. § 794(a); 45 C.F.R. §§ 84.4(a), 84.52(a)(1); 28 C.F.R. § 41.51(a).

²⁵ 45 C.F.R. § 84.4(b)(1)(i); 28 C.F.R. § 41.51(b)(1)(i).

²⁶ 45 C.F.R. §§ 84.4(b)(1)(ii), 84.52(a)(2); 28 C.F.R. § 41.51(b)(1)(ii).

²⁷ 45 C.F.R. §§ 84.4(b)(1)(vii), 84.52(a)(4); 28 C.F.R. § 41.51(b)(1)(vii).

²⁸ 45 C.F.R. §§ 84.4(b)(4) and 84.52(a)(4); 28 C.F.R. § 41.51(b)(3).

²⁹ *Southeastern Community College v. Davis*, 442 U.S. 397 (1979); *Henrietta D. v. Bloomberg*, 331 F.3d 261, 273-76 (2d Cir. 2003).

³⁰ 42 U.S.C. § 6102.

³¹ O.C.R. Bulletin dated March 28, 2020, <https://www.hhs.gov/about/news/2020/03/28/ocr-issues-bulletin-on-civil-rights-laws-and-hipaa-flexibilities-that-apply-during-the-covid-19-emergency.html>.

- Exclude older adults who would be expected to fully recover from COVID-19 but who are believed to have lower long-term life expectancy from receiving life-saving intervention despite the “successful treatment of acute illness.”³²
- Prevent older adults from accessing life-saving resources by factoring younger patients’ “opportunity to experience life stages.” This approach reaches outside of clinical considerations of recovery and health, and devalues the future lives of older adults. It introduces subjective notions of whose life is more valuable - which always cuts against older adults.”³³

Section 1557 of the Affordable Care Act (ACA) incorporates several federal civil rights statutes, including Title VI, Section 504, the ADA, and the Age Act, to prohibit discrimination on the basis of disability, race, color, national origin, sex, or age, in healthcare programs and activities that receive federal funding.³⁴ Thus, many of the violations itemized below and throughout this Complaint also constitute illegal discrimination against older Arizonans and individuals from communities of color. ADHS receives funding from the U.S. Department of Health and Human Services (HHS), and is therefore required to comply with the nondiscrimination mandate in the ACA, and is subject to OCR jurisdiction. Individuals can bring discrimination claims under Section 1557 based on the intersectionality of two or more of the protected classes identified in the statute (e.g. discrimination on the basis of age and disability or disability and race).³⁵

Arizona’s CSC and Addendum violate the ACA and its implementing regulations by authorizing actions that:

- Deny the benefits of, or otherwise subject a person with a disability, older adult, or person on the basis of race to, “discrimination under any health program or activity to which this part applies.”³⁶
- Fail to “make reasonable modifications to policies, practices, or procedures when such modifications are necessary to avoid discrimination on the basis of disability....and age.”³⁷

³² *Id.*; Addendum at 6.

³³ *Id.*; Addendum at 8.

³⁴ 42 U.S.C. § 18116.

³⁵ Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31405 (May 18, 2016); see also *Rumble v. Fairview Health Services*, No. 14-cv-2037, 2015 WL 1197415 (D. Minn. March 16, 2015).

³⁶ 45 C.F.R. § 92.101.

³⁷ 45 C.F.R. § 92.205.

Discrimination in the Arizona CSC and Addendum

The Arizona CSC and Addendum contain provisions that allow for discrimination in triage, the allocation of life-saving resources, and health-care decision-making, in violation of the non-discrimination requirements of the ADA, Section 504, the Age Act, Title VI, and the ACA. The Addendum both contains a number of provisions that explicitly or implicitly allow for discrimination against people with disabilities, older Arizonans, and individuals from communities of color; and lacks a number of provisions that are vitally necessary in order to prevent discrimination.

Consideration of Long-Term Mortality and “Life Stages”

The Addendum currently requires medical providers to consider long-term mortality when making health care allocation decisions. The Addendum's triage criteria include a point system under which individuals with a higher score have a lower priority for receiving lifesaving care. The Addendum requires triage officers to make predictions about long-term survivability, based upon projected life expectancy between one to five years, and then to allocate life-saving treatment based upon unreliable judgments. The professional literature provides no support for the reliability of such predictions.³⁸ To the contrary, scientific studies demonstrate that predicting life expectancy of up to five years is both unreliable and likely to reflect discriminatory attitudes, stereotypes, and unconscious bias against people with disabilities, older adults, and people from communities of color.

The CSC and Addendum reinforce current and historical inequities in access to health care, and risk importing quality of life criteria or unconscious bias into the triage process. Reliance on criteria like projected longevity in decision-making will inevitably have a discriminatory impact on people with disabilities, and those more likely to have underlying chronic conditions, including older adults and people from communities of color. Based on these predictions, individuals who are unlikely to survive one year or five years receive lower priority for lifesaving care.³⁹

People with disabilities and people from communities of color have long experienced discrimination in their access to medical and preventative health care.⁴⁰ Over time, this discriminatory treatment leads to more co-morbid conditions and lower than average longevity. For instance, people with psychiatric disabilities are among those with lower life expectancies due to co-morbidities associated with years of antipsychotic medication

³⁸ See <https://www.acponline.org/acp-newsroom/internists-say-prioritization-allocation-of-resources-must-not-result-in-discrimination> (American College of Physicians has rejected the use of long-term prognosis or “number of life years”).

³⁹ Addendum at 4.

⁴⁰ See, e.g., National Council on Disability, Organ Transplant Discrimination Against People with Disabilities (Sept. 25, 2019), https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf.

and related side effects, a history of segregation and substandard treatment, and marginalization in access to health care.⁴¹

Likewise, communities of color have also experienced discrimination and marginalization in the delivery of health care, issues which continue in various forms today.⁴² People of color are more likely to experience co-morbid medical conditions like asthma, diabetes, hypertension, and heart conditions,⁴³ as a result of structural racism, environmental factors, occupational safety and health, and lack of access to health care.⁴⁴ These health conditions can directly or indirectly factor into a healthcare provider's triage opinions about life expectancy (especially when used in conjunction with the SOFA scoring system discussed below), and result in de-prioritization for intensive care for those with disabilities, older adults, and people from communities of color.

Moreover, if more than one patient requires a single resource, the Addendum also allows for consideration of the opportunity for an individual to experience "life stages," such as childhood, young adulthood, middle years, and older years. This consideration inherently discriminates against older adults.⁴⁵

These considerations of long-term survival and "life stages" reach outside of clinical considerations and require providers to make healthcare allocation decisions that discriminate against people with disabilities and older adults. These requirements are

⁴¹ World Health Organization, Information Sheet: Premature death among persons with severe mental disorders (reporting 10-25 year life expectancy reduction) https://www.who.int/mental_health/management/info_sheet.pdf; Thomas Insel, Post by Former NIMH Director Thomas Insel: No Health Without Mental Health, Nat'l Instit. of Mental Health (September 6, 2011)(Citing studies that "Americans with major mental illness die 14 to 32 years earlier than the general population."), <https://www.nimh.nih.gov/about/directors/thomas-insel/blog/2011/no-health-without-mental-health.shtml>; M. De Hert, et al., Physical Illness in Patients with Severe Mental Disorders, 10 World Psychiatry 52 (2011) (people with SMI receive inadequate treatment by health care providers; "...stigmatization, discrimination, erroneous beliefs and negative attitudes associated with SMI will have to be eliminated to achieve parity in health care access and provision."); N. Liu, et al., Excess Mortality in Persons with Severe Mental Disorders: A Multilevel Intervention Framework and Priorities for Clinical Practice, Policy and Research Agendas, 16 World Psychiatry 30 (2017) (Although persons with serious mental illness have two times as many health care contacts, they receive fewer physical check-ups and screenings, fewer prescriptions and less treatment for physical ailments than other patients).

⁴² For instance, African American women are three to four times more likely to die during or after child birth than are white women. Amy Roeder, America is Failing its Black Mothers, Harvard Public Health Magazine (Winter 2019) available at https://www.hsph.harvard.edu/magazine/magazine_article/america-is-failing-its-black-mothers/.

⁴³ U.S. Dep't Health & Human Services, Office of Minority Health, Profile Black/African American ("The death rate for African Americans is generally higher than whites for heart diseases, stroke, cancer, asthma, influenza and pneumonia, diabetes, HIV/AIDS, and homicide."), <https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=61>.

⁴⁴ Jamila Taylor, Racism, Inequity and Health Care for African Americans, (The Century Foundation 2019), <https://tcf.org/content/report/racism-inequality-health-care-african-americans/?agreed=1>.

⁴⁵ Addendum at 8.

discriminatory on their face and will disproportionately impact hard hit⁴⁶ older adults in communities of color, such as African American⁴⁷ and Native American⁴⁸ communities who suffer from lower life expectancies due to well-documented social disparities and systemic health inequities. Further, these considerations are also not individualized assessments because they necessitate a reliance on longevity statistics.

*To address this discriminatory consideration, the Addendum must remove language permitting the use of a patient's long-term life expectancy or consideration of opportunity experience "life stages" as a factor in the allocation and re-allocation of scarce medical resources, instead indicating that providers should consider only risk of imminent mortality.*⁴⁹

Improper Reliance on Assessment Scoring Tools Without Ensuring Reasonable Modification

The Addendum instructs providers to use assessment scoring tools, including but not limited to the SOFA (Sequential Organ Failure Assessment) and/or the PELOD-2 (Pediatric Logistic Organ Dysfunction) tools, when charged with assessing the likelihood of survival or making health care allocation decisions.⁵⁰ Without the requirement that reasonable modifications be made to such assessment tools, these tools will lead to discrimination against persons with disabilities by providing inaccurate assessments based upon disability related characteristics, thus de-prioritizing people with disabilities for receipt of lifesaving care. For example, the Glasgow Coma Scale, which is an element of SOFA, evaluates lack of purposeful movement and ability to verbally respond. For certain individuals, these factors pertain to their underlying disabilities (including, for example, Alzheimer's dementia) and not their prognosis for recovery from COVID-19. Other SOFA elements can also give higher scores to people with disabilities.⁵¹

⁴⁶ Native Americans make up 3.9% of the population in Arizona but represent 6.8% of COVID-19 cases and 16.5% of deaths, <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-address-coronavirus/>.

⁴⁷ See, Allan S. Noonan, et al., Improving the Health of African Americans in the USA: An Overdue Opportunity to for Social Justice, 37 Oub. Health Rev. 12 (2016), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5810013/>.

⁴⁸ Indian Health Service, Fact Sheet: Disparities, <https://www.ihs.gov/newsroom/factsheets/disparities/>.

⁴⁹ Examples of plans that have avoided use of this kind of factor include Tennessee's Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency (https://www.tn.gov/content/dam/tn/health/documents/cedep/ep/Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf at 8), revised in consultation with OCR as part of a complaint resolution. Another example is the California State SARS-CoV-2 Crisis Care Guidelines (<https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/COVID-19/California%20SARS-CoV-2%20Crisis%20Care%20Guidelines%20-June%208%202020.pdf>).

⁵⁰ Addendum at 4, 5.

⁵¹ For example, a person with a history of polio and respiratory insufficiency may have low PaO₂/FiO₂ when off non-invasive mechanical ventilation. A person with rheumatoid arthritis can have chronically low platelets due to immune thrombocytopenia. People with sickle cell anemia often have chronically high bilirubin levels. A person with quadriplegia due to a spinal cord injury can have chronically low blood

To address this reliance on assessment tools without modification, language must be added to the Addendum to require reasonable modifications to any scoring instrument (e.g. SOFA) for assessing likelihood of immediate short-term survival, and short-term imminence of mortality, when necessary for accurate use with patients with underlying disabilities. Such reasonable modifications ensure that people with disabilities are evaluated based on their actual mortality risk, not disability related characteristics unrelated to the likelihood of survival.⁵²

Failure to Prohibit Illegal Decision-Making Considerations

The Addendum does not currently contain language prohibiting the consideration of resource intensity and duration of need as criteria for the allocation or re-allocation of scarce medical resources. People with disabilities or older adults who are likely to survive COVID-19 in the short-term may require additional health-care resources for a longer period of time in order to survive. It is prohibited discrimination to deny these individuals lifesaving care because they may need additional resources for a longer period of time as a result of disability or age.

By failing to explicitly prohibit resource intensity and duration of need as considerations in allocating life-saving treatment resources, the Addendum implicitly allows such considerations to be used in making these decisions.

To address this issue and protect patients who require additional treatment resources for a longer period of time due to disability or age from automatically being given a lower

pressure due to autonomic dysregulation. A person with polycystic kidney disease with renal insufficiency can have chronically elevated creatinine level. These underlying disability-related issues would all give these individuals higher SOFA scores, and deprioritize them for life-saving care.

⁵² Examples of states that have incorporated revised language on SOFA scoring in their respective state Crisis Standards of Care in order to avoid penalizing patients for underlying disabilities or co-morbid conditions that do not impact short-term survivability, include: Massachusetts, Pennsylvania, Delaware, Tennessee, and California. See e.g., Massachusetts (“Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,” April 20th 2020, 17, <https://archives.lib.state.ma.us/bitstream/handle/2452/825966/on1151409501.pdf>); Pennsylvania (“Pennsylvania’s Interim Crisis Plan,” April 10, 2020, Version 2, 30, <https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID19%20Interim%20Crisis%20Standards%20of%20Care.pdf>); Delaware (Delaware Health and Social Services, Crisis Standards of Care Concept of Operations, April 28, 2020, (7.6.2lii), <https://www.centerforpublicrep.org/wpcontent/uploads/2020/05/DE-CSC-ConOps-FInal-4-29-20.pdf>); Tennessee (Tennessee Altered Standards of Care Workgroup, “Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee,” July 2016 (updated June 2020), 2, Attachment B at 5, https://www.tn.gov/content/dam/tn/health/documents/cedep/ep/Guidance_for_the_Ethical_Allocation_of_Scarce_R_esources.pdf); and California (California SARS-CoV-2 Pandemic Crisis Care Guidelines: Concept of Operations Health Care Facility Surge Operations and Crisis Care (June 2020), 26, <https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/COVID-19/California%20SARSCoV-2%20Crisis%20Care%20Guidelines%20-June%208%202020.pdf>).

*priority to receiving lifesaving care, clear language must be added to the Addendum to clarify that resource intensity and duration of need due to disability or age may not be used as criteria for the allocation or re-allocation of medical resources.*⁵³

Failure to Include Prohibitions on Considering Pre-existing Conditions

Although the Addendum contains the general requirement that all patients be individually assessed and that treatment decisions be made without regard to disability, the Addendum lacks any language prohibiting assumptions about a person's "health" or pre-existing conditions or diagnoses. This could have the effect of discriminating against persons with disabilities, older adults, and people from communities of color because such assumptions disproportionately impact these groups, since they are more likely to have underlying health conditions or diagnoses. Assumptions about life expectancy or mortality associated with certain diagnoses or health conditions are by definition not individualized assessments.

By failing to explicitly prohibit consideration of pre-existing conditions in allocating life-saving treatment resources, the Addendum implicitly allows such conditions to be used in making these decisions.

To address this potential for discriminatory bias in decision-making, the Addendum must include an affirmative statement that assessments must be individualized and must not be based on assumptions about a person's perceived health, pre-existing condition (i.e. HIV/AIDS, cancer, diabetes, heart disease, Alzheimer's dementia) or diagnosis.

Failure to Include Short-Term Survivability as the Relevant Standard for Allocating Life-Saving Treatment

The Addendum does not contain any requirements related to short-term survivability as the sole criteria when determining an individual's prognosis, and thus eligibility for life-saving treatment. The absence of language requiring that short-term survivability and restoration to near the person's individual baseline health status will encourage decisions based upon stereotypes, perceived worth, and unconscious bias, and thus discriminate based upon subjective quality-of-life assumptions. For example, an individual may have a chronic condition that requires use of a ventilator. It is essential that when a healthcare

⁵³ An example of how this has been incorporated into a state Crisis Standards of Care plan can be seen in the California State SARS-CoV-2 Crisis Care Guidelines (<https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/COVID-19/California%20SARS-CoV-2%20Crisis%20Care%20Guidelines%20-June%208%202020.pdf> at 5), and the Tennessee Altered Standards of Care Workgroup "Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee," July 2016 (updated June 2020) (https://www.tn.gov/content/dam/tn/health/documents/cedep/ep/Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf at 8 ("categorical exclusions should be avoided. In addition, resource intensity and duration of need on the basis of age or disability should not be used as criteria."))

provider considers the ability to “recover” from COVID-19, that the relevant question is the ability to restore the patient to near his or her own baseline, and not the recovery that a person with no disabilities might achieve.

By failing to explicitly require short-term survivability as the sole criteria for allocating life-saving treatment resources, the Addendum implicitly allows other improper considerations to be used in making these decisions.

To address this, the Addendum must include clear language that when determining prognosis, only short-term survivability should be considered in allocating life-saving treatment with a focus on restoration to near the person’s individual baseline health status prior to the acute illness.

Failure to Prohibit Allocation Decisions Based on Past Use of Resources

The Addendum does not include any prohibition against health care allocation or re-allocation decisions based upon a person's past use of social or medical resources, or future need for such resources.⁵⁴ Consideration of the past or future need for social or medical resources in healthcare decisions likely results in discrimination by denying lifesaving care to persons with disabilities and older adults because such individuals often require home and community-based services (i.e. personal care assistance, therapies, transportation) and ongoing medical care.

By failing to explicitly prohibit the past use or future need for resources in allocating life-saving treatment resources, the Addendum implicitly allows such considerations to be used in making these decisions.

To address this, the Addendum must include clear language that decisions related to the allocation or re-allocation of healthcare resources must not consider the past use, or future need, for social or medical resources.

Failure to Require Reasonable Modifications

The Addendum also does not contain any requirement for the provision of reasonable modifications to policies and practices, auxiliary aids and services for effective communication, or language interpretation services when necessary to ensure equal access to medical care. People with disabilities may require auxiliary aids and services for effective communication, such as an American Sign Language interpreter, in order to be able to understand and participate in decision-making concerning their medical care. Persons with disabilities or older adults may also require additional reasonable

⁵⁴ An example of how this has been incorporated into a state Crisis Standards of Care plan can be seen in the California State SARS-CoV-2 Crisis Care Guidelines, <https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/COVID-19/California%20SARS-CoV-2%20Crisis%20Care%20Guidelines%20-June%208%202020.pdf> at 5.

modifications to policies and practices, such as additional assistance with mobility needs, or a modification to a no-visitors policy, in order to have equal access to medical care. Additionally, language interpretation must be provided for people with Limited English Proficiency under Title VI to ensure equal access to medical care and informed decision-making.

Many hospitals within Arizona have adopted strict no-visitor policies that do not provide for reasonable modifications to these policies for persons with disabilities who require a support person or family member to assist with disability-related needs while the person with a disability is hospitalized. These policies have prevented patients with disabilities from receiving support from family members or staff necessary for them to effectively communicate with medical personnel or otherwise receive equal access to medical treatment, deprived them of their right to make informed decisions and provide informed consent, and resulted in harms such as unnecessary physical and chemical restraints. These broad bans are creating a hardship on people with disabilities and resulting in violations of federal civil rights laws. Although this issue has been brought to the attention of ADHS, the only action that has been taken is issuance of a “reminder” letter to hospitals on the obligations of the ADA.⁵⁵ This falls short of the clear guidance necessary to address this issue and allows healthcare facilities and providers to discriminate against persons with disabilities by failing to provide reasonable modifications to restrictive visitation policies. In short, reasonable modifications are not required, and are not being provided. Since the issuance of the letter, ACDL continues to receive calls that hospitals and healthcare providers continue to deny visitors despite the issuance of the “reminder.”

Family, support persons, peer supports, and caregivers of people with disabilities (including older adults) have specialized knowledge and have often developed techniques to communicate with the individual, or have an understanding of the physical and mental health needs of the individual, that may not be apparent to other health care professionals. Denial of the rights of persons with disabilities to have access to these support individuals results in the denial of equal access to medical care and decision-making.

Other states have acted to assure that visitation bans are modified to accommodate the needs of patients with disabilities. For example, this Office recently commended the issuance of an Executive Order that resolved complaints concerning the State of Connecticut’s narrow visitation policy by “requiring hospitals and other acute care settings to permit the entrance of a designated support person for a patient with a disability and permitting family members, service-providers or other individuals knowledgeable about the needs of the person with a disability to serve as a designated support person [during

⁵⁵ See <https://www.azdhs.gov/documents/licensing/ltr-ada-hospitals.pdf>. This letter was only created by ADHS after advocacy organizations, including several involved in this Complaint, requested that direction be provided to Arizona hospitals on this issue by the State. The ADHS letter is extremely vague, mentioning only a requirement for a “caregiver” to assist patients with disabilities, and provides none of the safeguards that are discussed in the italicized paragraph below.

the COVID-19 pandemic].”⁵⁶ Arizona has failed to act by requiring these same types of essential accommodations to prevent discrimination against people with disabilities.

By failing to explicitly require reasonable modifications to assessment instruments and other aspects of the medical treatment and treatment allocation process, the Addendum directly contravenes discrimination laws that require such modifications.

*To address these issues, language must be added to the Addendum to require that reasonable modifications, auxiliary aids and services, and language interpretation services be provided where necessary to ensure people equal access to medical care and decision-making. Further, language that specifically requires reasonable modifications to restrictive visitor policies when a patient with a disability needs the presence of a family member, personal care assistant, or similar disability service provider knowledgeable about the management of their care, to physically or emotionally assist them, or to ensure effective communication during their hospitalization, is also essential. There may be a requirement that this be allowed with proper precautions to contain and prevent the spread of infection.*⁵⁷

Failure to Provide Notice of Medical Decision Appeal Rights

Although the Addendum currently provides family members or decision-makers the right to appeal triage decisions,⁵⁸ it does not contain a requirement that patients, caregivers, family members, and decision-makers be informed of those rights. The Addendum also fails to provide any requirements related to this appeal process. The right to appeal is effectively denied if there is not a decision deadline or a requirement to provide written notice to individuals on how to file an appeal, with whom to file the appeal, and when to

⁵⁶ U.S. Health and Human Services, *OCR Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19* (June 9, 2020), <https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>. The Connecticut Executive Order is available at: <https://portal.ct.gov/-/media/Coronavirus/20200609-DPH-Order-regarding-patients-with-disabilities-in-health-care-facilities.pdf>.

⁵⁷ See, e.g., HHS Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (March 28, 2020), <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>; “OCR Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19,” (June 9, 2020), <https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>. For additional examples of state Crisis Standards of Care plans that appropriately address this issue, see Tennessee’s Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency (https://www.tn.gov/content/dam/tn/health/documents/cedep/ep/Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf), and the California State SARS-CoV-2 Crisis Care Guidelines (<https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/COVID-19/California%20SARS-CoV-2%20Crisis%20Care%20Guidelines%20-June%208%202020.pdf>)

⁵⁸ Addendum at 8, 10.

expect a decision. It is likely that individuals will be effectively denied the right to appeal if there are not requirements regarding the designation of staff to receive appeals, process appeals, and make decisions on appeals.

To address this, clear language must be added to the Addendum requiring that providers ensure that patients, caregivers, and family members are given notice regarding the right to appeal triage decisions and the details of the appeal process. The Addendum must also include clear language instructing facilities on how to structure the appeal process to ensure decisions are made in a manner that is consistent and clear to impacted individuals asserting their right to appeal triage decisions.⁵⁹

Conclusion

We request that HHS OCR immediately investigate the issues regarding the Arizona CSC and Addendum raised in this Complaint and require the State of Arizona to take urgent corrective action to prevent discrimination in medical care in Arizona during COVID-19. We also request that OCR require any corrective action to include the necessary modifications and additions to the Addendum as set forth above. Once the necessary modifications and additions to the Addendum are completed, we request that OCR require the State of Arizona to incorporate the revised Addendum into the CSC. Additionally, we request that OCR require the dissemination of the revised Addendum immediately upon completion of the revisions.

Urgent action is required given the pace at which the pandemic is spreading in Arizona. Triage decisions based on these criteria could be made literally any day now. Life and death decisions should not be made that illegally discriminate against people with disabilities, older adults, and individuals from communities of color.

We thank you in advance for your prompt consideration of this urgent matter. Please feel free to contact us at mabela@azdisabilitylaw.org, adietrich@azdisabilitylaw.org, or 602-274-6287 with any questions or responses to this Complaint.

Sincerely,

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⁵⁹ For an example of a state Crisis Standard of Care plan that ensures these critical decisions are handled appropriately and in accordance with the law, see Massachusetts "Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic," April 20th 2020, <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download-at-24-25>.

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Complaint Against ADHS
July 17, 2020
Page 20

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