



# **Advocating for Equitable Health Care in a Public Health Emergency**

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# Who is the Arizona Center for Disability Law (ACDL)?

- ACDL is a non-profit law firm that assists Arizonans with disabilities to promote and protect their legal rights to independence, justice, and equality.
- ACDL envisions a society where people with disabilities enjoy full acceptance without barriers.



# ACDL is a Protection & Advocacy Agency (P&A)

- A P&A agency is a federally funded agency that works to enforce the rights of people with disabilities to be free from abuse and neglect, free from discrimination, and free from other rights violations.
- ACDL is the P&A for Arizonans with disabilities.



# Learning Objectives

- Crisis Standards of Care
- Nondiscrimination laws applied to the provision of healthcare
- ACDL's advocacy efforts
- Where are we now?



# Crisis Standards of Care



# What are Crisis Standards of Care (CSC)?

- CSCs are a plan developed by State public health authorities to provide guidance on the allocation of scarce health-care resources during a public health emergency
- CSCs are implemented when the need for health-care resources is greater than the availability of health-care resources
- Arizona CSC developed by Arizona Department of Health Services (ADHS)



# Arizona CSC

- The 3rd ed. of the Arizona CSC (2020) provides guidance on the activation, operation, and demobilization of the State Disaster Medical Advisory Committee (SDMAC)
- Provides guidance that SDMAC considers in developing incident specific guidance
- Triage guidelines and considerations for healthcare facilities
- Strategies for using and allocating scarce healthcare resources



# CSC COVID-19 Addendum

- ADHS activated the SDMAC in March 2020 after the COVID pandemic was declared a public health emergency
- SDMAC issued to health-care facilities the COVID-19 Addendum to the CSC with incident specific triage guidelines in the event that healthcare needs exceed resources



# Implementation of CSC

- On June 29, 2020, ADHS activated the CSC, authorizing healthcare systems and hospitals to implement the rationing and triage protocols in the COVID-19 Addendum if the event that available healthcare resources are exceeded by healthcare needs
- At the time of initial implementation the COVID-19 Addendum included provisions that violated nondiscrimination laws and would allow healthcare providers to violate nondiscrimination laws



# **Nondiscrimination Laws Applied to the Provision of Healthcare**



# What is a disability?

- A physical or mental impairment that substantially limits one or more major life activities.
- Major life activities include walking, breathing, seeing, speaking, hearing, caring for one's self, learning, relationships with others, etc.
- Major life activities include the operation of bodily functions such as respiration, circulation, endocrine, neurological, muscular etc.
- 42 U.S.C. § 12102
- Same definition in Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act



# Covered entities

- Title II of the ADA covers public entities:
  - *any State or local government*
  - *any department, agency, instrumentality of State or local government*
- Section 504 covers recipients of federal financial assistance, including State agencies that receive Medicaid funds



# Title II of the ADA, Section 504

- Public entities and recipients of federal financial assistance may not:
  - *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.*
  - *"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."*



# More requirements

- Covered entities may not:
  - “[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.”
  - “[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.”



# Covered entities may not:

- “Directly or through contractual or other arrangements, utilize criteria or other methods of administration:
  - *That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability;*
  - *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*
  - *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.”*



# Covered entities must:

- “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.”



## Covered entities may not:

- “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.”



# Section 1557 of the Affordable Care Act

- Prohibits discrimination on the basis of disability, race, color, national origin, sex or age in health-care programs and activities that receive federal funding (e.g. State agencies and private health care providers that receive Medicaid funding)
- Claims under Section 1557 are based on the intersection of 2 or more of the protected classes



# Discrimination in the Arizona CSC 3rd ed. and COVID-19 Addendum first ed.

- The CSC violated each of the provisions discussed above in a number of ways
- Considerations of long-term mortality and "life stages"
  - *Required triage officers to make predictions about long-term survivability of up to 5 years and allocate treatment based upon these unreliable and biased assumptions*



# COVID-19 Addendum

- Predicting long-term life expectancy is unreliable and reflects discriminatory attitudes and bias against people with disabilities
- People with disabilities often have a statistically shorter life expectancy precisely because they are denied care based on quality-of-life and social worth assumptions



# Improper reliance on assessment tools

- Addendum allowed for improper reliance on assessment scoring tools without requiring reasonable modifications for disability related traits
- For example, the lack of purposeful movement is a symptom of many mobility disabilities, and this would have given a person a lower score and give them a lower priority for care unless assessment tools were modified



# Resource intensity and duration of need

- Without an explicit ban, the Addendum allowed resource allocation decisions to be based upon the amount and duration of needed resources
- Screening out people with disabilities who may require greater treatment resources for a longer period of time, or long-term care services
- Consideration of past use of resources



# Consideration of pre-existing conditions

- Addendum did not contain any prohibition on triage officers considering existing medical conditions when allocating health-care resources
- Allowed for assumptions based upon perceived health or diagnoses
- Existing respiratory illnesses, HIV, cancer, heart disease



# Failure to require reasonable modifications in policy and procedure

- No requirement that auxiliary aids and services be provided to patients during the public health emergency
- No requirement that visitation policies be modified to allow family or caregivers to visit individuals who need assistance with daily activities



# Failure to provide notice of appeal rights

- Addendum did not contain a requirement that patients and families be notified of the right to appeal triage decisions



# **ACDL's Advocacy Arizona COVID-19 Crisis Standards of Care**



# Concern from the Community

- Very concerning accounts of discrimination in other states re: decisions made in medical triage during COVID-19
- Outreach to ACDL through intakes





# Initial Advocacy



- April 10, 2020 - letter from ACDL to ADHS and DDD
- June 23, 2020 – joint letter from ACDL, The Arc of Arizona, Arizona Center for Law in the Public Interest, Ability360, and others



# Complaint – U.S. Department of Health and Human Services Office for Civil Rights (OCR)

- Complaint filed on July 17, 2020
- On behalf of two individual complainants, ACDL, The Arc of Arizona, Arizona Center for Law in the Public Interest, and Native American Disability Law Center



# OCR Complaint

- Requested that OCR require ADHS to take the following actions:
  - *Prohibit health-care decision-making based on long-term life expectancy.*
  - *Prohibit decision-making to be based on the intensity and duration of the need for healthcare resources.*
  - *Require reasonable modifications to any triage assessment scoring tools to assess mortality only in the short-term.*



# OCR Complaint

- Requested that OCR require ADHS to take the following actions:
  - *Prohibit decision-making to be based upon the existence of pre-existing health conditions.*
  - *Explicitly require short-term survivability as the standard for healthcare and resource allocation decisions.*
  - *Require reasonable modifications to visitation policies.*
  - *Require the provision of auxiliary aids and services needed for effective communication.*



# OCR Complaint – Technical Assistance

- OCR technical assistance process
- Outreach and direct continued conversation with ADHS and Governor's Office
- December 2020 – formal request for joint technical assistance by complainants and ADHS



# OCR Complaint Resolution



- January 2021 - complainants provide suggested updated draft COVID-19 Addendum to ADHS based on OCR technical assistance feedback
- February 2021 – negotiations on COVID-19 Addendum language
- March 2021 – Agreement between ADHS and complainants reached on language, sent to OCR for approval



# OCR Complaint Resolution

- May 2021 - OCR approved the revised COVID-19 Addendum as a resolution of the pending complaint
- Updated COVID-19 Addendum Arizona Crisis Standards of Care: <https://www.azdhs.gov/covid19/documents/healthcare-providers-sdmac/covid-19-addendum.pdf>
- OCR Press Release: <https://www.hhs.gov/about/news/2021/05/25/ocr-provides-technical-assistance-state-arizona-ensure-crisis-standards-care-protect-against-age-disability-discrimination.html>



# CSC Legislation – H.B. 2386

- Concern: how to prevent this issue from arising in a future public health crises?
- Worked with policy organization that had found a sponsor for a bill that memorialized the key non-discrimination principles we worked to incorporate into the COVID-19 Addendum



# CSC Legislation – H.B. 2386

- HB2386 would require any CSC adopted or established by ADHS specify:
  - *Each patient has a right to an individualized assessment;*
  - *A patient or a patient's health care decision-maker has the right to make the patient's healthcare choices, and have a right to appeal triage decisions;*
  - *Providers may not require a patient to sign a Do Not-Resuscitate order or make a particular health care decision;*
  - *Decisions on the allocation of health care resources may not discriminate on the basis of disability, age, race, religion, sex, veteran status or income status;*



# CSC Legislation – H.B. 2386

- HB2386 would require any CSC adopted or established by ADHS specify:
  - *Persons with disabilities and the aged have the right to reasonable accommodations to ensure that all patients have equal access to medical care; and,*
  - *Health care providers may consider only survival from the episode of care that directly resulted from the injury or illness that required hospitalization, instead of unreliable, biased and inappropriate factors such as perceived or actual disability, age, quality of life assessments, long-term mortality, life expectancy, or resource intensity and duration of need due to disability or age.*



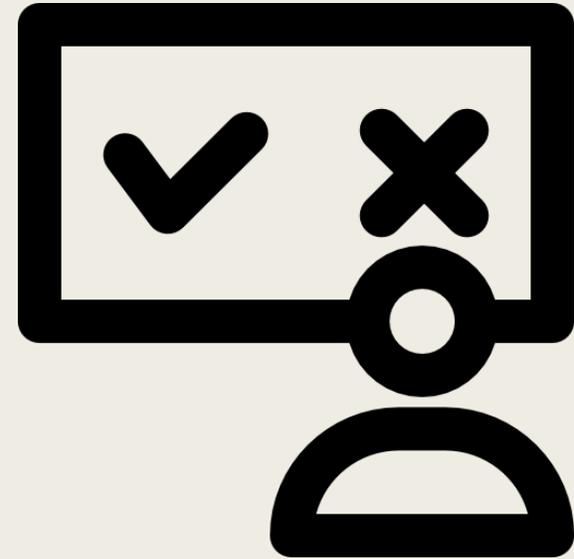
# CSC Legislation – H.B. 2386

- H.B. 2386 also requires state P&A to be part of the SDMAC
- Ensures that disability advocates are part of the process of creating future CSCs from the beginning, helping to ensure that any CSCs, if necessary, are not discriminatory



# CSC Legislation – H.B. 2386

- Passed in the AZ 2021 Legislative Session and was signed by AZ Governor Doug Ducey on July 9, 2021
- Legislation took effect September 29, 2021





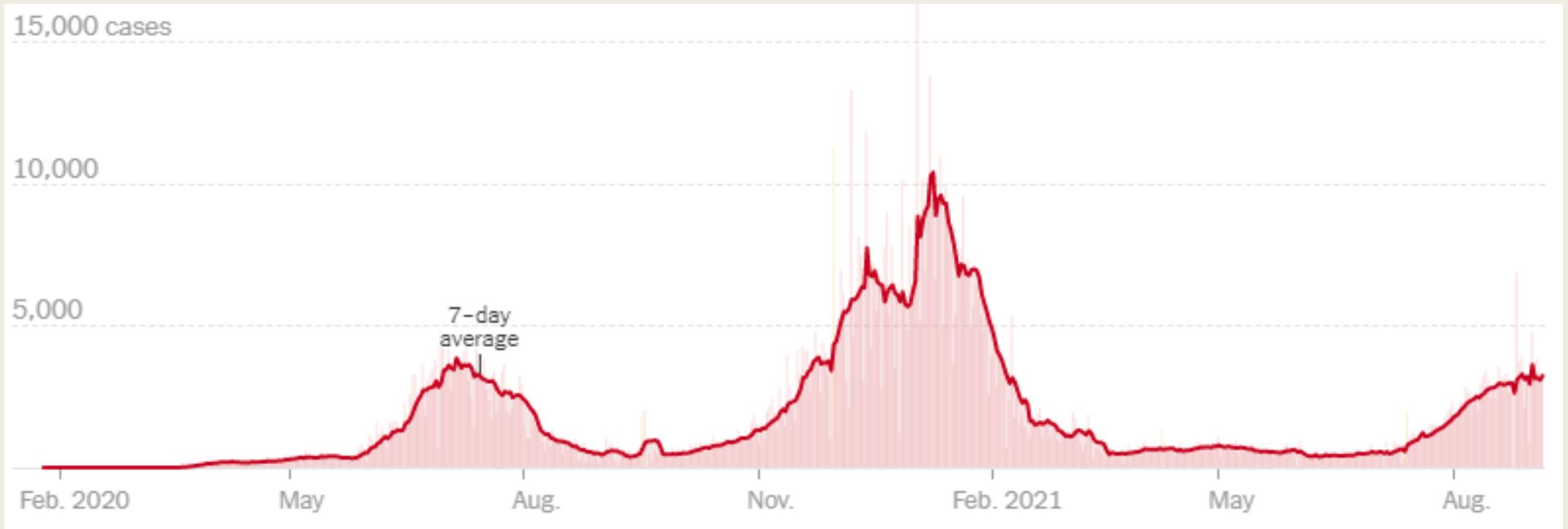
**Where are we now?**



# October 2020 v. October 2021

**2020**

**2021**





**Questions?**