

# Advocacy and Preparedness: Healthcare Rationing in Times of Crisis



Today's presentation is dedicated to our loved ones lost too soon and the many New Mexicans who came together and sacrificed to help their fellow New Mexicans through difficult times

**WINTON WOOD**

# Objectives

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- Gain an understanding of protections in place regarding healthcare and people with disabilities
- Identify concerns with rationing policies
- Gain an introduction to understanding guiding principles for avoiding discrimination in treatment rationing
- Identify ways to support equitable treatment during times of healthcare rationing

What comes to mind when you  
hear the word

triage or rationing?

*Speak up! Or write in the chat!*



# What is triage?

(in medical use): the assignment of **degrees of urgency** to wounds or illnesses to decide the **order of treatment** of a large number of patients or casualties.

- *Oxford Languages*

*Triage WWI, 42nd Division, near Sieppes, France 1918*

[www.worldwar1centennial.org](http://www.worldwar1centennial.org)

# MARCH 2020



# Policies addressing the allocation of resources in the event of a natural disaster or pandemic

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## **IDEALLY:**

- Neutral decision making directives

## **REALITY (many):**

- Outdated
  - Discriminatory
- “quality of life” “worth”

# Protections are already in place

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- **Section 504 of Rehabilitation Act (1973/1977)**
  - Prohibits discrimination against people with disabilities by entities that receive federal financial assistance.
- **Americans with Disabilities Act – A.D.A. (1990)**
  - Title II of the ADA prohibits state and local governments from discriminating against people with disabilities.
  - Title III prohibits places of public accommodation such as hospitals, clinics, and doctors' offices from discriminating against them.
- **Section 1557 of Affordable Care Act (2016)**
  - Prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities.

# Non discriminatory protections not being followed



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## ~~IDEALLY:~~

- Neutral decision making directives

## REALITY (many):

- Outdated
- Discriminatory
- “quality of life” “worth”



# Discriminatory Directives

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- Taking “dementia into account” (hospitals in AL, LA, PA, TX, UT)
- Considering “baseline functional status” (WA)
- Consider “taking ventilators away from patients who rely on them in daily life if others need them more” (CT, FL, IN, KS, MN, NY)
- Taking into account “likely” life expectancy
- No rationing policy

# What concerns you about these directives?

Considering dementia

Life “expectancy”

Baseline functional status

No rationing policy

Ventilator reassignment

*Speak up! Or write in the chat!*

# What about separation from hospitalized loved ones?

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- Hospital policies vary (often case by case approach)
- What happens to non-verbal patients? How can families know what decisions the hospital staff take in regards to “triage”?
- Does the patient (or family) know that having a family member or other support person stay with them is an accommodation under the Americans with Disabilities Act?

# Pushback

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- State and local advocates write letters to their governors and state health departments
- National advocacy organizations mobilize
- Legal complaints are filed with the Office of Civil Rights  
<https://medicaid.publicrep.org/feature/covid-19/>

# Triage – pediatric patients

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## STEP 1: Screen Pediatric Patients for ICU care During Scarce Resources

Proceed to the following after reviewing goals of care with patient and family (e.g. limited code status). The goals of care should reflect the best interest of the patient.

For the following conditions consider available staffing and resources. If resources are inadequate, consider transferring the following patients to out-patient or palliative care with appropriate resources and support as can be provided.

- 1. Pre-existing or Persistent encephalopathy, coma or vegetative state
- 2. Severe acute trauma (e.g. non-survivable head injury)
- 3. Severe burns with Low Survival burn scores based on the Triage Decision for Burn Victims table (See Table A). See Burn Scarce Resource Card for management of critical burn patient outside of a Burn Center.
- 4. Significant underlying disease process that predict poor short term survival\*

*\*Examples of underlying diseases that predict poor short-term survival, despite standard treatment, include but are not limited to:*

- Known severe chromosomal abnormalities with poor prognosis*
- Known severe metabolic, neuromuscular, cardiac, oncologic or pulmonary disease with poor prognosis*
- Extreme prematurity at the limits of viability*

# Triage – adult patients

## STEP 1: Screen adult patients for ICU care during scarce resources

Proceed to following after reviewing patient's end of life directives/POLST or similar living will documents. For the following conditions consider available staffing and resources. If resources are inadequate, **consider** transferring the following patients to out-patient or palliative care with appropriate resources and support as can be provided.

1. Pre-existing or Persistent coma or vegetative state
2. Severe acute trauma (e.g. non-survivable head injury)
3. Severe burns with Low Survival burn scores based on the Triage Decision for Burn Victims table (See Table A below). See Burn Scarce Resource Card for management of critical burn patient outside of a Burn Center.
4. Significant underlying disease process that predict poor short term survival\*  
*\*Examples of underlying diseases that predict poor short-term survival, despite standard treatment, include but are not limited to:*
  - Severe congestive heart failure
  - Severe chronic lung disease
  - Central nervous system, solid organ or hematopoietic malignancy with poor prognosis for recovery
  - Severe cirrhotic liver disease with multi-organ dysfunction
5. Baseline functional status (consider loss of reserves in energy, physical ability, cognition and general health)

# Pennsylvania

**Table 1. Patient Prioritization Tool to Allocate Critical Care/Ventilators During a Public Health Emergency**

Principle	Specification	Point System*			
		1	2	3	4
Save the most lives	Prognosis for short-term survival (SOFA score*)	SOFA score < 6	SOFA score 6-8	SOFA score 9-11	SOFA score ≥ 12
Save the most life-years	Prognosis for long-term survival (medical assessment of comorbid conditions)	...	Major comorbid conditions with substantial impact on long-term survival	...	Severely life-limiting conditions; death likely within 1 year

\*SOFA= Sequential Organ Failure Assessment, which is used as an example of how to integrate an objective measure of acute severity of illness.  
 \*\* Persons with the lowest cumulative score would be given the highest priority to receive mechanical ventilation and critical care services.

**Table 2. Examples of Major Comorbidities and Severely Life Limiting Comorbidities**

Examples of Major comorbidities (associated with significantly decreased long-term survival)	Examples of Severely Life Limiting Comorbidities (associated with survival < 1 year)
<ul style="list-style-type: none"> <li>Moderate Alzheimer’s disease or related dementia</li> <li>Malignancy with a &lt; 10 year expected survival</li> <li>New York Heart Association (NYHA) Class III heart failure</li> <li>Moderately severe chronic lung disease (e.g., COPD, IPF)</li> <li>End stage renal disease</li> <li>Severe, inoperable multi-vessel CAD</li> </ul>	<ul style="list-style-type: none"> <li>Severe Alzheimer’s disease or related dementia</li> <li>Metastatic cancer receiving only palliative treatments</li> <li>New York Heart Association (NYHA) Class IV heart failure</li> <li>Severe chronic lung disease with FEV1 &lt; 25% predicted, TLC &lt; 60% predicted, or baseline PaO2 &lt; 55mm Hg</li> <li>Cirrhosis with MELD score ≥20</li> </ul>

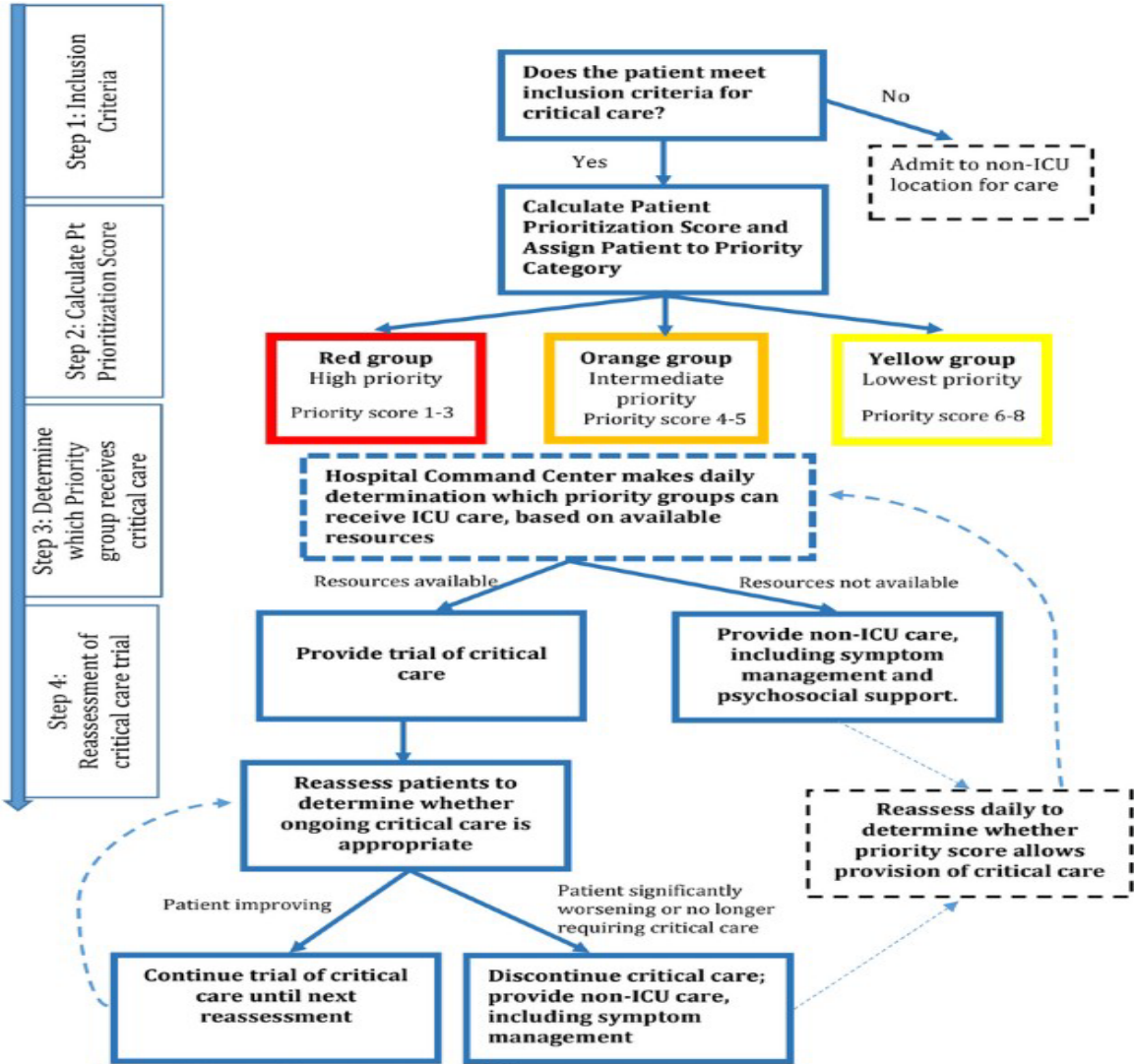


Figure 6: Patient Prioritization Model

# March 28, 2020-Bulletin from the Health & Human Services Office of Civil Rights Affirming Nondiscrimination\*

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*“HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal. Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies [...] Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism.”*

*- Roger Severino, OCR Director*

\*<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>



# Guiding principles for avoiding discrimination in treatment rationing



In April 2020, over 200 disability and healthcare organizations developed or endorsed guiding principles, applying the Health & Human Services Office of Civil Rights guidance in a publication:

“Applying HHS’s Guidance for States and Health Care Providers on Avoiding Disability-Based Discrimination in Treatment Rationing”

# Main tenets

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- The lives of people with disabilities are equally worthy and valuable as those of people without disabilities.
- People with disabilities must have an equal opportunity to receive life-sustaining treatment.
- The fact that an individual with a disability requires support (minimal or extensive) to perform certain activities of daily living is not relevant to a medical analysis of whether that individual can respond to treatment.
- Doctors and triage teams must refrain from employing assumptions and stereotypes about the worth or quality of the life of a person with a disability in making decisions about medical treatment.

- Doctors and triage teams must not assume that they are free from conscious or unconscious bias in making critical life and death health care decisions, given the reality that people with disabilities have long experienced discrimination in receiving medical care.
- To avoid discrimination, doctors or triage teams must perform a thorough individualized review of each patient and not assume that any specific diagnosis is determinative of prognosis or near-term survival without an analysis of current and best available objective medical evidence and the individual's ability to respond to treatment.
- Doctors and triage teams must not reallocate ventilators of individuals with disabilities who use ventilators in their daily lives and come to the hospital with symptoms of COVID-19. Individuals with disabilities who use ventilators in their daily lives should be allowed to continue to use this personal equipment if they receive COVID-19 treatment at a hospital.

- Federal disability rights laws—including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act—broadly protect people with disabilities against discrimination in receiving medical treatment. These laws apply to hospitals experiencing a medical equipment, bed, or staffing shortage during the COVID-19 pandemic as well as state policies concerning how resources should be allocated in the event of such shortages.

Download document here: <https://dredf.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals-FINAL.pdf>

Also contains recommendations for hospitals developing triage plans and other related resources

So What About New Mexico?

# NM Triage Guidelines

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- New Mexico Statewide Acute Medical Care Surge Plan for COVID-19 Pandemic response April 2020  
<https://cvmodeling.nmhealth.org/wp-content/uploads/sites/4/2020/05/NM-CSC-Plan-V.4.17.20.pdf>
- New Mexico Triage Protocol for the Allocation of Scarce Resources Under COVID-19 Crisis Standards of Care – Executive Summary May 2020  
[https://cvmodeling.nmhealth.org/wp-content/uploads/sites/4/2020/05/NMMATAssessmentTriageProtocol2020\\_05\\_22.pdf](https://cvmodeling.nmhealth.org/wp-content/uploads/sites/4/2020/05/NMMATAssessmentTriageProtocol2020_05_22.pdf)
- Appendix E: NM Triage Protocol for the Allocation of Scarce Resources Under COVID-19 CSC (Version October 25, 2021) – Allocation of Ventilators  
<https://cv.nmhealth.org/wp-content/uploads/2021/11/Appendix-E.-Update-Triage-Protocol.pdf>

# Scoring guide for the allocation of ventilators and scarce resources

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- Takes into account “severely life-limiting conditions” (pg 5):

**Table 1. Scoring Strategy to Allocate Ventilators During a Public Health Emergency**

Specification	Point System*			
	1	2	3	4
Prognosis for short-term survival (SOFA score#)	SOFA score < 6	SOFA score 6-8	SOFA score 9-11	SOFA score ≥12
Prognosis for long-term survival (medical assessment of comorbid conditions)	...	...	...	Severely life-limiting conditions; death likely within 1 year



# “Severely life limiting comorbidities”

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Include, among others (pg 6)

- Dementia or a **similar progressive neurocognitive disorder** (must be calculated with baseline)
- Advanced Progressive Neurodegenerative Disorder, such as **Amyotrophic Lateral Sclerosis, Multiple Sclerosis and Parkinson’s disease**

- “Patients who have no major or life-limiting comorbidities score 0 points.
- “A patient who has one or more severely life-limiting comorbidity receives a score of 4 points on the Priority Score.”
- “A single score of 0 or 4 will be applied to the Priority Score.”
- “The scores reflecting symptom severity (the SOFA) (Table 1) and comorbidity (Table 2) are added to create a patient’s Priority Score, which will range from 1 to 8. High scores reflect high severity and low likelihood of survival following intensive medical treatment. Patients with lower scores are thus prioritized to receive available ventilators or other scarce healthcare resources.”

Scoring Guide (pg 6)

# New Mexico – Medical Advisory Team (MAT)

*Reports to Governor; Secretary of Health; Secretary of Human Services*

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MAT composed of three main groups that report the Department of Health (DOH) Leadership Team:

- Operations Group
- Hospital and Health System Group
- Crisis Standards of Care Workgroups

# New Mexico – Medical Advisory Team (MAT)

*Reports to Governor; Secretary of Health; Secretary of Human Services*

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- Operations Group:
  - The MAT chair, administrative leadership assigned to support MAT, Department of Corrections liaison, chairs of the Hospital and Health System Group, chairs of each of the **Crisis Standard of Care Workgroups**, and DOH officials as needed.
- Hospital and Health System Group:
  - The Hospital and Health System Group is composed of representatives of the designated key referral hospitals (hubs), Indian Health Service, and the Albuquerque Area Veterans Affairs Hospital. One member of the group will serve as chair

# New Mexico – Medical Advisory Team (MAT)

*(continued)*

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➤ Crisis Standards of Care Workgroups:

➤ The MAT will establish workgroups as necessary to carry out its purpose and functions. **These workgroups may establish subgroups as necessary.** The initial workgroups include:

- Regional Care
- Clinical Care
- Transportation
- Modeling and Analytics
- Workforce
- Behavioral Health
- Legal and Ethics
- Communication

# Colorado



- Potential role model in protecting disability rights
- Galvanized the community including in triage policy
- “Our Crisis Standards of Care\* guidelines are informed by ethicists, physicians, and experts, **including those in the Colorado disability community** who have been intimately involved with the response to the COVID- 19 pandemic.”  
– *Lt. Governor Dianne Primavera*

<https://cdphe.colorado.gov/colorado-crisis-standards-care>

# Colorado

<https://cdphe.colorado.gov/colorado-crisis-standards-care>

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- Disallows medical “rationing” based on disability alone
- **Prevents other discrimination by establishing a blinded triage process**
- Specifies that all hospitals in Colorado have a plan for providing effective communication accommodations with/for people who are disabled, and
- Clarifies that no person who uses a ventilator as part of their regular care will have their ventilator taken away or receive less than equitable care

Source: NDSC-GLOBAL-NDSS Webinar: *No Discrimination in Healthcare Rationing* April 2020

# So What About New Mexico?

**Is there room for improvement?**

*Speak up! Or write in the chat!*





## What can YOU do?

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Take a look at the resources and references and make your own determinations. **Remember that knowledge is power.**

- New Mexico Triage Protocols/ Crisis Standards of Care
- “Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care”
- Guidance to State Hospitals- National Advocacy Organizations
- “Applying HHS’s Guidance for States and Health Care Providers on Avoiding Disability-Based Discrimination in Treatment Rationing”



## What can YOU do?

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- **Knowledge is power:** examine personal bias, get to know people with disabilities so as to better understand their value and strengths in society. **SHARE THIS KNOWLEDGE**
- **Check-in** with your Healthcare Employer to encourage adherence to disability non-discrimination laws.



# BE PREPARED

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- **Develop/research** an “Assessment of the Patient with a Disability Checklist” example: [https://www.nln.org/docs/default-source/uploadedfiles/professional-development-programs/ace-series/assessment-of-pwd-checklist-rev-7-19-17.pdf?sfvrsn=12b2a80d\\_0](https://www.nln.org/docs/default-source/uploadedfiles/professional-development-programs/ace-series/assessment-of-pwd-checklist-rev-7-19-17.pdf?sfvrsn=12b2a80d_0)
- **Create** an emergency preparedness toolkit for yourself and those with disabilities  
<https://nobodyisdisposable.org/know-your-rights/>



# BE PREPARED

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Emergency preparedness toolkit for yourself and those with disabilities (cont) <https://nobodyisdisposable.org/know-your-rights/>

- Do you have in place: Durable Medical Power of Attorney; Durable Financial Power of Attorney; Advance Directives; Will or Trust
- Create a “Connection Kit”
- Know what to take to the hospital
- Who to bring
- Strategies for advocacy, including potential survival strategies to consider if you or a loved ones face discrimination



## What can YOU do?

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- **Check** with advocacy organizations, and the state's Triage Protocol Team; **who are members of this team? Are there self-advocates and family members?**



# What can YOU do?

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“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.”

Margaret Mead



# Questions?

*Speak up! Or write in the chat!*

# Resources to examine

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- Bulletin from the Health & Human Services Office of Civil Rights Affirming Nondiscrimination 3/28/2022: <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>
- New Mexico Triage Guidelines:
  - <https://cvmodeling.nmhealth.org/wp-content/uploads/sites/4/2020/05/NM-CSC-Plan-V.4.17.20.pdf>
  - [https://cvmodeling.nmhealth.org/wp-content/uploads/sites/4/2020/05/NMMATAssessmentTriageProtocol2020\\_05\\_22.pdf](https://cvmodeling.nmhealth.org/wp-content/uploads/sites/4/2020/05/NMMATAssessmentTriageProtocol2020_05_22.pdf)
  - <https://cv.nmhealth.org/wp-content/uploads/2021/11/Appendix-E.-Update-Triage-Protocol.pdf>
- “Applying HHS’s Guidance for States and Health Care Providers on Avoiding Disability-Based Discrimination in Treatment Rationing” : <https://dredf.org/avoiding-disability-based-discrimination-in-treatment-rationing/>
- <https://thearc.org/covid-19-response/>
- Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Healthcare, Laura Guidry-Grimes et al., <https://onlinelibrary.wiley.com/doi/full/10.1002/hast.1128>



# References

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- <https://www.worldwar1centennial.org/index.php/delivery-of-medical-care-on-the-battlefield/2597-delivery-of-medical-care-on-the-battlefield-triage-and-the-field-hospital-section.html>
- *Burn and Blast Casualties: Triage in Nuclear War*, Jennifer Learning, MD Harvard Community Health Plan, Boston, Massachusetts [www.ncbi.nlm.nih.gov/books/NBK219175/](http://www.ncbi.nlm.nih.gov/books/NBK219175/)
- “Disability Rights Advocates’ Objections to States Critical Care Allocation Frameworks”, MM Mello et al, The New England Journal of Medicine 2020;383:e26.
- <https://usafacts.org/visualizations/coronavirus-covid-19-spread-map/state/colorado>
- National Down Syndrome Congress, Global Down Syndrome Foundation & National Down Syndrome Society Webinar April 14, 2020
- Bulletin from the Health & Human Services Office of Civil Rights Affirming Nondiscrimination 3/28/2022: <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>
- - American Association of People with Disabilities Campaign Against Discrimination in Triage: <https://nobodyisdisposable.org>
- National Down Syndrome Congress: <https://dredf.org/avoiding-disability-based-discrimination-in-treatment-rationing/>
- Washington State DOH: <https://www.doh.wa.gov/Emergencies/COVID19>
- Comprehensive Hospital Preparedness Checklist for Coronavirus Disease 2019 (COVID-19): <https://www.cdc.gov/coronavirus/2019-ncov/hcp/hcp-hospital-checklist.html>
- <https://www.ohiocitizen.org/>
- <https://cvmodeling.nmhealth.org/wp-content/uploads/sites/4/2020/05/NM-CSC-Plan-V.4.17.20.pdf>
- <https://thearc.org/covid-19-response/>
- Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Healthcare, Laura Guidry-Grimes et al., <https://onlinelibrary.wiley.com/doi/full/10.1002/hast.1128>