



No Discrimination in Health Care Rationing Webinar

Protecting the
Rights of Individuals
with Disabilities



Tuesday, April 14 | 2:00 PM Eastern



Agenda

- Healthcare rationing: why & how
- Local, state and national advocacy against discriminatory rationing
- COVID-19 and Down syndrome: Risks and Resources
- Colorado advocacy and treatment model
- Separation from loved ones with DS in hospitals
- HHS Office of Civil Rights: guidance and process
- Questions?



What does the NDSC do?

- **Provide accurate and up-to-date information about Down syndrome** to families and the professionals who serve them – in English and Spanish. Present timely webinars that provide practical tips and tools for attendees. Exhibit at medical conferences to provide resources for clinics at no charge (like the *Prenatal Testing Pamphlet* created with our partners at Global Down Syndrome Foundation).
- Through our **Center for Outreach & Education**, conduct one-day conferences in underserved areas, driven in content by the requests of the local organization and the families they serve and provide CEU-generating training for Educators to enhance outcomes for their students with Down syndrome, autism, and other intellectual and developmental disabilities.
- Work with our **vast network of local, regional, and national partners and affiliate organizations** on various projects and initiatives, to grow our dynamic community.
- Host our one-of-a-kind **NDSC Annual Convention**, with world-renowned speakers, the latest and greatest information on an array of topics, a huge exhibit hall, awards to celebrate people making an impact in the community, and don't forget the dancing!
- Hard at work for you in Washington, our **top-notch Policy & Advocacy Team** helps you take action and stay informed.

NDSC Policy & Advocacy Team

- NDSC Mission: *to provide information, advocacy & support concerning all aspects of life for individuals with Down syndrome.*
- Policy priorities across the lifespan
 - Education (K-12, Transition, Postsecondary)
 - Medicaid and Long-Term Services & Supports, Health Care
 - Employment and financial security
 - Protect the rights of people with disabilities across all areas
- Coalition work
 - Consortium for Citizens with Disabilities
 - Collaboration to Promote Self-Determination
 - Leadership Conference on Civil & Human Rights
 - Inclusive Higher Education Task Force (and many more)
- National Down Syndrome Advocacy Coalition



Healthcare rationing: why and how

- Triage has existed for centuries on battlefields
- Most states already have policies that address the allocation of resources, like ventilators, in the event of a natural disaster or pandemic.
 - Crisis standards of care
 - Some policies have been updated in response to COVID-19
- Ideally, those policies set neutral decision-making rules based on the individual medical condition of the patient.
- Some of these established rationing policies are outdated and discriminatory, making assumptions about a person's quality of life or their "worth" relative to others

Discriminatory rationing policies

- Hospitals in AL, LA, PA, TX and UT direct hospitals to “take dementia into account”
- In WA, doctors should consider “baseline functional status,” including “loss of reserves in energy, physical ability, cognition and general health.”
- CT, FL, IN, KS, MN and NY: hospitals should consider taking ventilators away from patients who rely on them in daily life if others need them more
- Many policies also take into account how many more years patient is likely to live (yet many people with disabilities live longer than their initial prognoses)
- Some states don’t have rationing policies so decision is left up to individual hospitals or providers, making them ripe for personal bias

State & local advocates are pushing back

- Letters to Governors and State Departments of Health asking them to issue guidance to hospitals and other healthcare providers regarding their obligations under the ADA and other federal disability non-discrimination laws to individuals with disabilities during all phases of treatment
 - Example - Kentucky
<http://nebula.wsimg.com/22ef11968d4a5f12780bfe07d0e65e08?AccessKeyId=65CDDA A309ED09126F01&disposition=0&alloworigin=1>
 - Example – Colorado
- Governors are responding to such requests
 - Letter from Governor ([PA](#))
 - Letter from State Dept of Health ([CA](#))



Check with your state's P&A to see if a similar letter has already been sent and, if not, work with them to send one.

National advocacy orgs are fighting back

- Legal complaints with Office of Civil Rights (OCR) of Health & Human Services have been filed in 7 states so far: WA, AL, KS, TN, PA, UT, & NY
 - More info about OCR complaints: <https://medicaid.publicrep.org/feature/covid-19/>
 - Early resolution in AL: "Alabama and other states are free to and encouraged to adopt clear triage policies, but they must do so within the guardrails of the law."
- AAPD Campaign Against Discrimination in Triage #NoBodyIsDisposable
 - Rights and resources at: <https://nobodyisdisposable.org>
- Developed guiding principles for avoiding discrimination in treatment rationing (based on recent OCR/HHS guidance)
 - NDSC joined 200 other disability and health care organizations: <https://dredf.org/avoiding-disability-based-discrimination-in-treatment-rationing/>

Guiding principles for avoiding disability discrimination in treatment rationing

- 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.

Guiding principles (cont'd)

- 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

NDSC Statement on Discriminatory Medical Treatment Rationing During COVID-19 Crisis

- “We want to emphasize that making this decision on the basis of disability is in violation of federal disability nondiscrimination laws...”.
- “NDSC will continue to remain vigilant and advocate for people with Down syndrome and other disabilities to be given the same treatment and opportunities as people without disabilities.”
- “Not only is medical rationing based on disability illegal discrimination, but it is also morally reprehensible.”
- Complete statement can be found here:
<https://www.ndsccenter.org/ndsc-statement-on-discriminatory-medical-treatment-rationing-during-covid-19-crisis/>

What can you do to prevent this discrimination?

- Stay home, be extra vigilant
- Get pediatrician or other trusted doctor involved as your advocate
- Call the Office of Civil Rights 1-800-368-1019 or email OCRMail@hhs.gov
- Report incidents to your state's P&A organization (www.ndrn.org) and your states Center for Independent Living (CIL) (www.ilru.org)
- Report incidents to NDSC, Global, NDSS
- Print HHS guidance and bring with you to hospital (or take photos with phone)
- Advocate in your state for Governor or State Department of Health to issue strong statements condemning medical rationing discrimination.

Sign up to stay up-to-date with NDSC Policy communications!

- *Read our monthly Policy e-newsletter, the Newsline*
- *Join the National Down Syndrome Advocacy Coalition*
- *Action Alerts*
 - <https://www.ndsccenter.org/political-advocacy/take-action-stay-informed/>
- *Facebook – National Down Syndrome Congress Policy & Advocacy*
 - <https://www.facebook.com/dsadvocates/>
- *Twitter*
 - *@NDSCPolicy*



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GLOBAL

DOWN SYNDROME FOUNDATION®



No Discrimination
in Health Care
Rationing Webinar



Protecting the
Rights of Individuals
with Disabilities

Tuesday, April 14 | 2:00 PM Eastern



Medical issues for people with Down syndrome and other disabilities

By: Michelle Sie Whitten
President & CEO

Tuesday, April 14, 2020

Global Down Syndrome Foundation

A Unique Affiliate Model

The Global Down Syndrome Foundation is the largest non-profit in the U.S. working to save lives and dramatically improve health outcomes for people with Down syndrome. Global has donated more than \$32 million to establish the first Down syndrome research institute supporting over 400 scientists and over 2,000 patients with Down syndrome from 28 states and 10 countries.

Working closely with Congress and the National Institutes of Health, Global is the lead advocacy organization in the U.S. for Down syndrome research and care.

Global has a membership of over 100 Down syndrome organizations worldwide and is part of a network of Affiliates - the Crnic Institute for Down Syndrome, the Sie Center for Down Syndrome, and the University of Colorado Alzheimer's and Cognition Center - all on the Anschutz Medical Campus.



The Inspiration behind Global



Anna and John J. Sie



Sophia & Patrick Whitten

“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

Center for Disease Control & Prevention (CDC)

Who is Considered High Risk for COVID-19?

- ❖ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-at-higher-risk.html>
- ❖ COVID-19 is a new disease and there is limited information regarding risk factors for severe disease.
- ❖ **Higher risk means a person may be more likely to suffer severe illness from COVID-19.**
- ❖ Currently available information and clinical expertise categorize the following groups as higher risk for severe illness from COVID-19:
 - 1) Older adults (65 and up); 8 out of 10 deaths reported in the U.S. have been in adults 65 years old and older as of April 2, 2020.
 - 2) People in nursing homes or long-term care facilities.
 - 3) People of any age who have serious underlying medical conditions



Older Adults



People with Asthma



Groups at Higher Risk for Severe Illness



People with HIV

CDC: “Underlying Medical Conditions” that are High Risk for COVID-19

High Risk = People of all ages with underlying medical conditions, particularly if not well controlled, including:

- 1) **People with chronic lung disease or moderate to severe asthma**
 - Includes obstructive sleep apnea (OSA) and Chronic obstructive pulmonary disease (COPD) that can lead to both lung and heart disease
 - NIH emphasizes respiratory difficulties
- 2) **People who have serious heart conditions**
- 3) **People who are immunocompromised**
 - Many conditions can cause a person to be immunocompromised, including cancer treatment, smoking, bone marrow or organ transplantation, immune deficiencies, poorly controlled HIV or AIDS, and prolonged use of corticosteroids and other immune weakening medications
- 4) **People with severe obesity (body mass index [BMI] of 40 or higher)**
- 5) **People with diabetes**
- 6) **People with chronic kidney disease undergoing dialysis**
- 7) **People with liver disease**

Why most people with Down syndrome will be considered High Risk for COVID-19

The following include some, not all, underlying medical conditions that are considerably more prevalent in people with Down syndrome as compared to people without Down syndrome:

1) People with chronic lung disease or moderate to severe asthma

- Obstructive sleep apnea (OSA) and Chronic obstructive pulmonary disease (COPD) that can lead to both lung and heart disease; Sleep apnea in people with Down syndrome is estimated to be 40-70%
- Respiratory difficulties

2) People who have serious heart conditions

- Most congenital heart defects that were corrected by surgery successfully should not count; chronic leaky valve or heart failure issues will likely be a problem

3) People who are immunocompromised

- Children with Down syndrome are much more likely to develop two kinds of cancer, but overall the percentage is still 1%+/-.

4) People with severe obesity (body mass index [BMI] of 40 or higher)

5) People with diabetes

6) People with chronic kidney disease undergoing dialysis

7) People with liver disease

Why most people with Down syndrome will be considered High Risk for COVID-19

❖ Many adults with Down syndrome, especially in urban areas, live in Group Homes that are considered High Risk

- <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html>
- To protect these vulnerable friends and family members, the CDC has advised that long-term care facilities:
 - 1) restrict visitors,
 - 2) regularly check healthcare workers and residents for fevers and symptoms, and
 - 3) limit activities within the facility to keep residents safe.

❖ **Additional Thoughts (Please see DS/COVID-19 Q&A Resource)**

- It may be more difficult for people with Down syndrome and IDD to comply with safeguards like social distancing or wearing masks.
- It may be more difficult for people with Down syndrome to articulate if they are feeling sick or how they are feeling.
- Behaviors associated with disrupted routines may be difficult.

CDC: Steps You Should Take If You are at High Risk Including those with DS

- ❖ <https://www.cdc.gov/coronavirus/2019-ncov/downloads/COVID19-What-You-Can-Do-High-Risk.pdf>
- ❖ If you are at higher risk for serious illness from COVID-19 it is extra important for you to take actions to reduce your risk of getting sick with the disease:
 - 1) Stay home if possible.
 - 2) Wash your hands often.
 - 3) Take everyday precautions to keep space between yourself and others (stay 6 feet away, which is about two arm lengths).
 - 4) Keep away from people who are sick.
 - 5) Stock up on supplies.
 - 6) Clean and disinfect frequently touched surfaces.
 - 7) Avoid all cruise travel and non-essential air travel.
 - 8) Call your healthcare professional if you have concerns about COVID-19 and your underlying condition or if you are sick.



Down Syndrome & COVID-19 Q&A

An Important Community Resource

- ❖ DSMIG-USA, GLOBAL, LuMind, NDSC, NDSS & NTG Q&A Consortium
- ❖ Available in both Expanded & Abbreviated versions.
- ❖ English and Spanish
 - Special thanks to Jesus Florez, MD PhD, and President, Fundación Iberoamericana Down 21, for providing the translation.
- ❖ Updated version available mid to late April.



Other National & International Support Organizations: Down Syndrome Affiliates in Action, GiGi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, T21 Research Society

Down Syndrome & COVID-19 Q&A

An Important Community Resource



Q&A on COVID-19 and Down Syndrome

Expanded Version • From March 26, 2020

ORGANIZERS:
DMIG-USA
Down Syndrome Medical Interest Group USA

SUPPORTING ORGANIZATIONS:
Down Syndrome Affiliates in Action, G/G's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, T21 Research Society

The unprecedented spread of the Coronavirus Disease 2019 (COVID-19) is presenting the world with a unique challenge and, in our case, calls for a united response to better understand its impact on the Down syndrome community.


Information in this Question and Answer (Q&A) document can be used to help you support your loved one with Down syndrome. It is our hope that this information will help us get through this health challenge. We encourage you to share the information in this document with your family, friends, educational and medical providers, and others within the Down syndrome community.

We have done our best to answer questions that are currently being asked and anticipate other important questions relevant to our Down syndrome community. In this document you'll find information about:

- What may be unique about the virus in people with Down syndrome.
- How to help prevent the spread of the virus.
- What some common symptoms are.
- What to think about when making decisions.


This Expanded Version and an Abbreviated Version of this Q&A are available. Many organizations and professionals have contributed to both versions by providing their expertise on Down syndrome and applying it to what we know about COVID-19 at this time. As we learn more about COVID-19 in general, and about how it may or may not affect people with Down syndrome, we will continue to update this Q&A.

To be clear, this Q&A is informational only and not intended to provide medical advice or related advice. It is intended to provide information that we hope is useful as you confront decisions and consider seeking medical, educational, or other recommendations. This Q&A should NOT be considered a substitute for the advice of a medical or related professional. You should consult with your own doctor or other healthcare professional(s) for medical advice.



Q&A on COVID-19 and Down Syndrome

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Q&A on COVID-19 and Down Syndrome

Abbreviated Version • From March 26, 2020

ORGANIZERS:
DMIG-USA
Down Syndrome Medical Interest Group USA

SUPPORTING ORGANIZATIONS:
Down Syndrome Affiliates in Action, G/G's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, T21 Research Society

Information in this Question and Answer (Q&A) document is here to help you care for your loved one with Down syndrome during the Coronavirus Disease 2019 (COVID-19) pandemic. Please share this information freely.

We have tried to answer questions that are important:

- What may be unique about the virus in people with Down syndrome.
- How to help prevent the spread of the virus.
- What common symptoms are.
- What to think about when making decisions.

This Abbreviated Version and an Expanded Version of this Q&A are available. Many experts have worked together to provide this information. As we learn more about COVID-19, we will update this Q&A - check our websites for updated versions.

This Q&A is not a substitute for the advice of your medical professional. You should consult with your doctor or other healthcare professional(s) for medical advice.

If you think you or anyone in your care may have COVID-19, call your doctor or other health professional immediately. Calling first is important. Going to an office or a hospital makes your risk of possibly catching or spreading the virus greater. If you call first, the office or hospital will be prepared for you. If you have an emergency, please call 911.

It's important to take care of yourself. If you are sick or too tired, you cannot care for others. Stay healthy! Others depend on you. When you can, check in with family and friends. They may have problems with this health emergency and could use your help.

Q1: Is general COVID-19 information about symptoms, spreading and preventing the virus, and treatment the same for people with Down syndrome?

A. Yes. Information about COVID-19 is the same for people with Down syndrome. Good information is best found at central sources like websites that end with .gov:

- Centers for Disease Control: [Coronavirus Disease 2019 \(COVID-19\) | CDC](https://www.cdc.gov/coronavirus/2019-ncov/index.html)
- National Institutes of Health: [Coronavirus \(COVID-19\) | NIH](https://www.nih.gov/coronavirus)
- Your state health department website has advice about where you live.

Q&A on COVID-19 and Down Syndrome

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Disability Discrimination Complaints Filed to the OCR

Against 7 States So Far: AL, KS, NY, PA, TN, UT, WA

[The Arc](#) and the [Center for Public Representation](#) (CPR) have taken the lead with other disability organizations to file complaints to the U.S. Department of Health and Human Services Office of Civil Rights (OCR) against the states of [Alabama](#), [Kansas](#), [Pennsylvania](#), New York, [Tennessee](#), Utah, and [Washington](#) for publishing or having COVID-19 related guidelines that would blatantly and illegally discriminate against people with disabilities.

ALABAMA (Filed: 3/24/2020)

Under the Alabama Department of Public Health's Emergency Operations Plan, for children and adults, hospitals are ordered to "not offer mechanical ventilator support for patients" with "severe or profound mental retardation," "moderate to severe dementia," and "severe traumatic brain injury."

- (Resolved: 4/8/2020) OCR announces that it has resolved a compliance review of the State of Alabama after the state removed ventilator rationing guidelines that allegedly discriminated on the basis of disability and age.

KANSAS (Filed 3/27/2020)

In Kansas, the state recently developed a protocol called the "Toolkit for COVID-19." The protocol specifically withholds life-saving treatment from patients based on their disability diagnosis - without an individualized assessment of their prospects for recovery - including people with "advanced untreatable neuromuscular disease," people with "advanced or irreversible immunocompromise," and people with some forms of cancer. In addition, hospitals could take away ventilators from individuals with disabilities or medical conditions who regularly use their own ventilators.

TENNESSEE (Filed: 3/27/2020)

The standing Guidelines for the Ethical Allocation of Scarce Resources in Tennessee exclude many people with disabilities from critical care, including ventilators. They further exclude people with metastatic cancer, some people with dementia, and some people with traumatic brain injury.

UTAH (Filed 4/6/2020)

NEW YORK (Filed 4/7/2020)

Disability Discrimination Complaints Filed to the OCR Against 7 States So Far: AL, KS, NY, PA, TN, UT, WA

PENNSYLVANIA (Filed: 4/2/2020)

The Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines were just published on March 22, 2020 and discriminate against and jeopardize the lives of people with disabilities. For children and adults, the “scoring” of who gets care and who doesn’t takes into account long-term survival. The guidelines also discriminate against people with preexisting conditions that are disabilities and those with “severely life-limiting” co-morbid diagnoses, which can be left to interpretation.

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

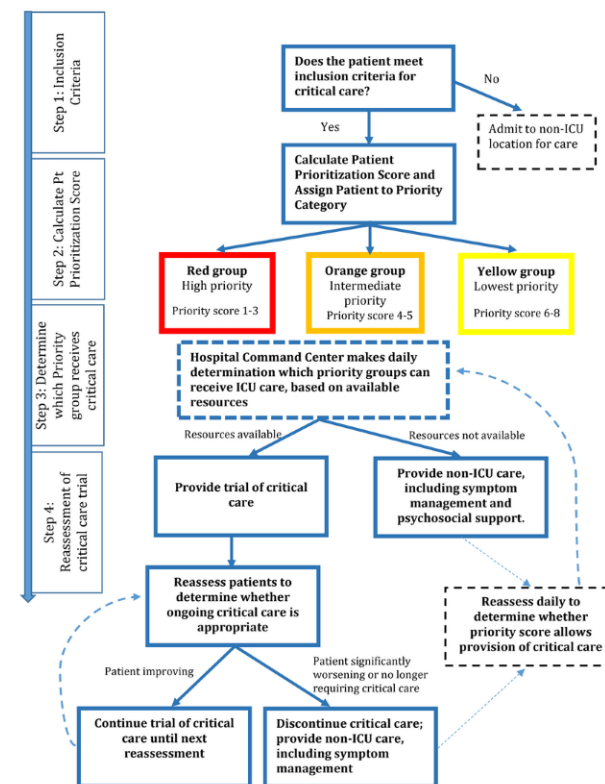


Figure 6: Patient Prioritization Model

Disability Discrimination Complaints Filed to the OCR Against 7 States So Far: AL, KS, NY, PA, TN, UT, WA

WASHINGTON (Filed 3/23/2020)

In Washington state, the Department of Health published descriptions of the goals and flow charts associated with emergency COVID-19 treatment that mirror the existing policy of the state-run University of Washington Medical Center (UWMC). Under this policy, the priority would be to uniformly treat people who are younger and healthier and to leave those who are older and sicker—including people with disabilities—to die.

- **Fairness** – Standards that are, to the highest degree possible, recognized as fair by those affected by them – including the members of affected communities, practitioners, and provider organizations, evidence based and responsive to specific needs of individuals and the population.
- **Duty to care** – Standards are focused on the duty of healthcare professionals to care for patients in need of medical care.
- **Duty to steward resources** – healthcare institutions and public health officials have a duty to steward scarce resources, reflecting the utilitarian goal of saving the greatest possible number of lives.
- **Transparency** – in design decision making, and information sharing.
- **Consistency** – in application across populations and among individuals regardless of their human condition (e.g. race, age disability, ethnicity, ability to pay, socioeconomic status, preexisting health conditions, social worth, perceived obstacles to treatment, past use of resources).
- **Proportionality** – public and individual requirements must be commensurate with the scale of the emergency and degree of scarce resources.
- **Accountability** – of individual decisions and implementation standards, and of governments for ensuring appropriate protections and just allocation of available resources.²

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

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 termsurvival*

**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)

CO Example of Disability Coalition Advocacy - *How local DS orgs can get involved*

Prevent and Prohibit Medical “Rationing” Based on Disability

- Decisions are not made based on permanent disabilities or underlying conditions unless:
 - ❖ There is a clinically definitive terminal diagnosis and the individual meets hospice guidelines.
 - ❖ There is a clinically definitive diagnosis that makes it highly unlikely that the person could survive the coronavirus based on a scientifically known multiple variables (e.g. age 70+ AND severe heart or lung disease that is not reversible).
- Restoration criteria must only look at restoration to baseline. The fact that someone will need to use medical or social resources after discharge cannot be a factor in decision-making if the person needed those resources prior to the acute treatment.
- All hospitals must have a plan for providing effective communication to people with disabilities including a reasonable accommodation process to assist with communication.
 - ❖ Examples could include materials accessible for people who are blind or low-vision, auxiliary aides and services for people with communication disabilities or Sign Language interpreters for people who are Deaf (CDPHE should provide a resource tool kit. CCDC can assist with this)
- The state is clear that no one who uses a ventilator on a regular basis (not related to COVID-19) will have their ventilator confiscated. Anyone already on a ventilator that is hospitalized for any other reason will be treated and the use of a ventilator will not reduce their triage score (someone already living on a ventilator may actually have greater survivability).
- Admission, discharge and aftercare criteria will not differ for people with disabilities and people without disabilities. If someone cannot safely go home once a hospital-level of care is no longer required, placement in a rehab or nursing facility must be short term and re-evaluated every 72 hours.

Colorado - A Potential Role Model in Protecting Disability Rights, Galvanizing the Community



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IN THE FACE OF ETHICAL ABERRATIONS IN SEVERAL STATES COLORADO STANDS STRONG AGAINST DISCRIMINATION IN COVID-19 CARE

140 Organizations Help Ensure People with Disabilities Will Receive Equitable Treatment under Colorado's Newly Published "Critical Care Triage Guidance for Crisis Standards of Care"

DENVER, April 9, 2020 - The Governor's Expert Emergency Epidemic Response Committee developed Crisis Standards of Care (CSC) after collaboration with experts and communities. Governor Polis has authorized the Colorado Department of Public Health and Environment to enact the standards when or if necessary.

The [Colorado Cross Disability Coalition](#) (CCDC), [The Arc of Colorado](#), and [over 140 organizations](#) thank Gov. Jared Polis for ensuring that people with disabilities and other vulnerable populations receive equitable care under the CSC during the COVID-19 epidemic and other crisis situations.

Specifically, the revised CSC Plan provides standards that hospitals and other health care practitioners should implement once activated by the Chief Medical Officer for the Colorado Department of Public Health and Environment (CDPHE): (1) disallow medical "rationing" based on disability alone, (2) prevent other discrimination by establishing a blinded triage process, (3) specify that all hospitals in Colorado have a plan for providing effective communication accommodations with/for people who are disabled, and (4) clarify 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.

Statement from Lt. Governor Dianne Primavera:

Every resident in this state deserves and should receive equitable care, even during the most uncertain of times.

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.

When a crisis like this hits, we must protect everyone's rights, civil liberties and health.

Group Homes in NYC with people with Intellectual & Developmental Disabilities are ravaged by COVID-19.
<https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>

Will we be separated from our loved ones with Down syndrome who have COVID-19?

What we know so far

- ❖ Hospital policies vary
- ❖ May be able to argue that having a family member or other support person stay is an accommodation under the Americans with Disabilities Act
- ❖ We know that some people without Down syndrome who have COVID-19 are being separated from their loved ones.
 - Communicating through nurses' or personal devices (e.g. FaceTime).
- ❖ Children's Hospital Colorado is taking a case-by-case approach.
 - Considerations include health of the family member, if the family member meets criteria for "high risk," or if they the primary caretaker for other individuals.
- ❖ Some hopeful cases: Three adult patients in Chicago, one grade-schooler in Colorado.
- ❖ Some terrible outcomes/troubling issues:
 - 46 year old with DS dies of COVID-19. <https://www.tampabay.com/news/hernando/2020/04/08/franca-panettone-46-hernando-countys-first-coronavirus-death/>
 - 30 year old with DS dies of COVID-19. <https://www.pix11.com/news/coronavirus/man-with-down-syndrome-dies-from-covid-19-one-week-after-his-mother>
 - 18 month old with DS can't get COVID-19 test in NY. <https://www.wkbw.com/news/coronavirus/lancaster-family-searching-for-covid-19-testing-for-their-18-month-old>

What can we do?

- ❖ Stay vigilant in protecting ourselves, our loved ones with Down syndrome, and our families.
- ❖ Have a plan in case you or your loved one with Down syndrome contracts COVID-19.
- ❖ Join the fight against medical care discrimination in your backyard or nationally.
- ❖ Help medical providers and group homes obtain Personal Protective Equipment such as masks.
- ❖ Advocate for other relief funding for people with disabilities.
- ❖ Read the DS/COVID-19 Q&A and share it widely.
- ❖ Ask for help. We are here for you and we are in this TOGETHER.

THANK YOU!



@GDSFoundation



@globaldownsyndrome



Ashley Helsing

Director of Government
Relations

National Down Syndrome Society

NDSS Areas of Programming

National Advocacy & Public Policy

Center creates systemic change through legislative advocacy

The **Inclusive Health and Wellness**

Program encompasses our National Buddy Walk® Program, #TeamNDSS and our healthy community all to create a healthier Down syndrome community

Down Syndrome Community Outreach

& Resources provides comprehensive and accurate information and resources on Down syndrome

Public Awareness initiatives bring new and positive presentations of Down syndrome to the general public



NDSS Mission & Vision

- **MISSION**

The mission of the National Down Syndrome Society is to be the leading human rights organization for all individuals with Down syndrome

- **VISION**

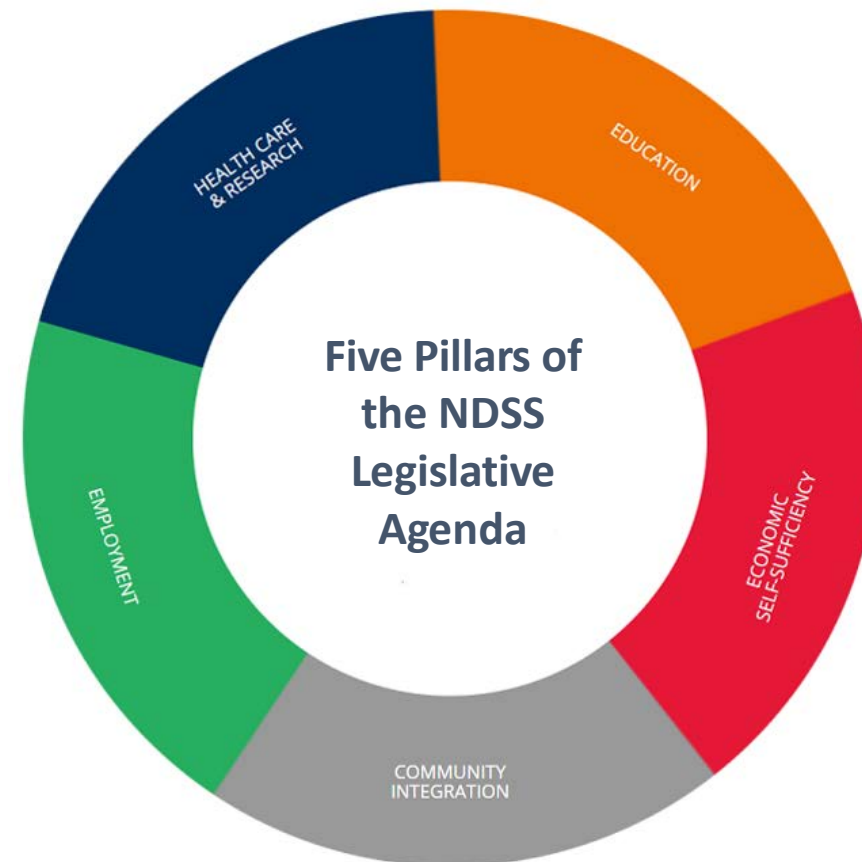
The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities



National Advocacy & Public Policy Center

Overview

Create systemic
change through
legislative advocacy



National Advocacy & Public Policy Center

Protections already in place

- **Americans with Disabilities Act**
 - 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 504 of Rehabilitation Act**
 - Prohibits discrimination against people with disabilities by entities that receive federal financial assistance.
- **Section 1557 of Affordable Care Act**
 - Prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities.

National Advocacy & Public Policy Center

NDSS Statement- March 26, 2020



Organizations representing individuals with disabilities, led by the Arc, recently filed a [complaint](#) with the U.S. Department of Health and Human Services Office for Civil Rights (OCR) highlighting the potential for widespread discrimination as health care professionals in the United States develop protocols for rationing life-saving treatment in response to possible COVID-19 resource scarcity. The complaint urges OCR to take immediate action to investigate such instances and to assist local jurisdictions and providers in developing non-discriminatory protocols that ensure access to life-saving treatments for individuals with disabilities.

As the leading human rights organization for all individuals with Down syndrome, the National Down Syndrome Society (NDSS) supports the complaint to OCR and will work with disability advocate groups to protect the civil rights and equal access to healthcare for those with Down syndrome and other disabilities. To help us stay vigilant in this effort, we ask you to let us know if you or someone you know with Down syndrome or other disabilities has had acute health care services or equipment denied or withdrawn, or been given a lower priority for treatment, due to scarce COVID-19 resources.

If you are aware of such discriminatory actions, please email Ashley Helsing, NDSS Director of Government Relations, at ahelsing@ndss.org.

National Advocacy & Public Policy Center

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

HHS Office for Civil Rights in Action



March 28, 2020

BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

“HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal,” said Roger Severino, OCR Director. “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,” Severino added.

Please click [HERE](#) for the full statement and [HERE](#) for the Bulletin.

National Advocacy & Public Policy Center

What is “triaging”?

When sufficient medical services aren’t available to every wounded soldier on a battlefield, doctors engage in triage. Those with the most severe wounds may be left to die – not because the doctors value their lives less, but because the doctors can save more people by concentrating on soldiers with less severe, but still life-threatening, wounds...

... Denying ventilators to coronavirus patients with preexisting disabilities is thus not at all the same as making a battlefield triage decision to do the greatest good for the greatest number.

Op-Ed by Chairman Neil Romano, National Council on Disability and Samuel Bagenstos, principal deputy assistant attorney general for civil rights under the Obama Administration.

National Advocacy & Public Policy Center

How does the HHS Office of Civil Rights Enforce civil rights discrimination laws and regulations?

1. Investigate complaints that allege discrimination.
2. If the evidence indicates that the covered entity was not in compliance, OCR will try to resolve the case through a voluntary agreement with the covered entity.
3. If the covered entity does not take voluntary action to resolve the issue satisfactorily, OCR will issue a "Letter of Findings" regarding the noncompliance of the covered entity.
4. The letter will include next steps, which could include a referral to the Department of Justice for enforcement action, steps to terminate Federal financial assistance, or other actions.

Click [HERE](#) for more information on the process.

Thank You!



Ashley Helsing

Director of Government Relations

National Down Syndrome Society

ahelsing@ndss.org

Ways to Engage:

- Follow us on [Facebook](#), [Twitter](#), [Instagram](#) and [LinkedIn](#)
 - Text “Law Syndrome” to 52886
- Submit your application to join the [DS-AMBASSADOR® Program](#)
 - Sign up for our [monthly newsletter](#)
- Call our Info Line at 1-800-222-4602 or email info@ndss.org
- Visit ndss.org for up-to-date information and resources on COVID-19



Questions?

- Heather Sachs,
heather@ndsccenter.org
- Michelle Sie Whitten,
mswhitten@globaldownsyndrome.org
- Ashley Helsing, ahelsing@ndss.org

