Intersections & Conflicts

The ADA and Impacts of the COVID-19 Protocols

July 5, 2022

Presented by: Emily Cooper, Joannie Tang and Tina Pinedo

DRO Disability Rights Oregon

Emily Cooper

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“Three weeks ago we celebrated our nation's Independence Day. Today we're here to rejoice in and celebrate another “independence day,” one that is long overdue. With today's signing of the landmark Americans for Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom. As I look around at all these joyous faces, I remember clearly how many years of dedicated commitment have gone into making this historic new civil rights act a reality. **It's been the work of a true coalition, a strong and inspiring coalition of people who have shared both a dream and a passionate determination to make that dream come true**.

…

Today's legislation brings us closer to that day when **no Americans will ever again be deprived of their basic guarantee of life, liberty, and the pursuit of happiness**.”

- George H.W. Bush during the Signing of the ADA at July 26, 1990

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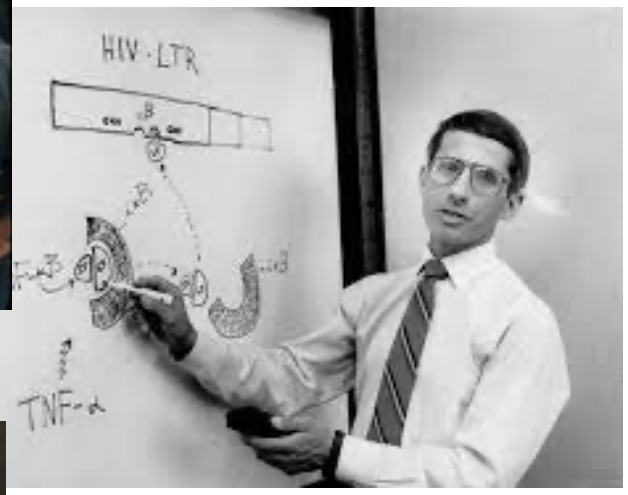
History of Health Care Discrimination

Public health officials' decisions and impact on communities:

- Buck v. Bell, SCOTUS decision on forced sterilization of people with disabilities (1927)
- Syphilis study at Johns Hopkins (1932 - 1972)
- Fauci's initial assumption that "AIDS can be transmitted by routine household contact" (published in 1983 Journal of the American Medical Association)



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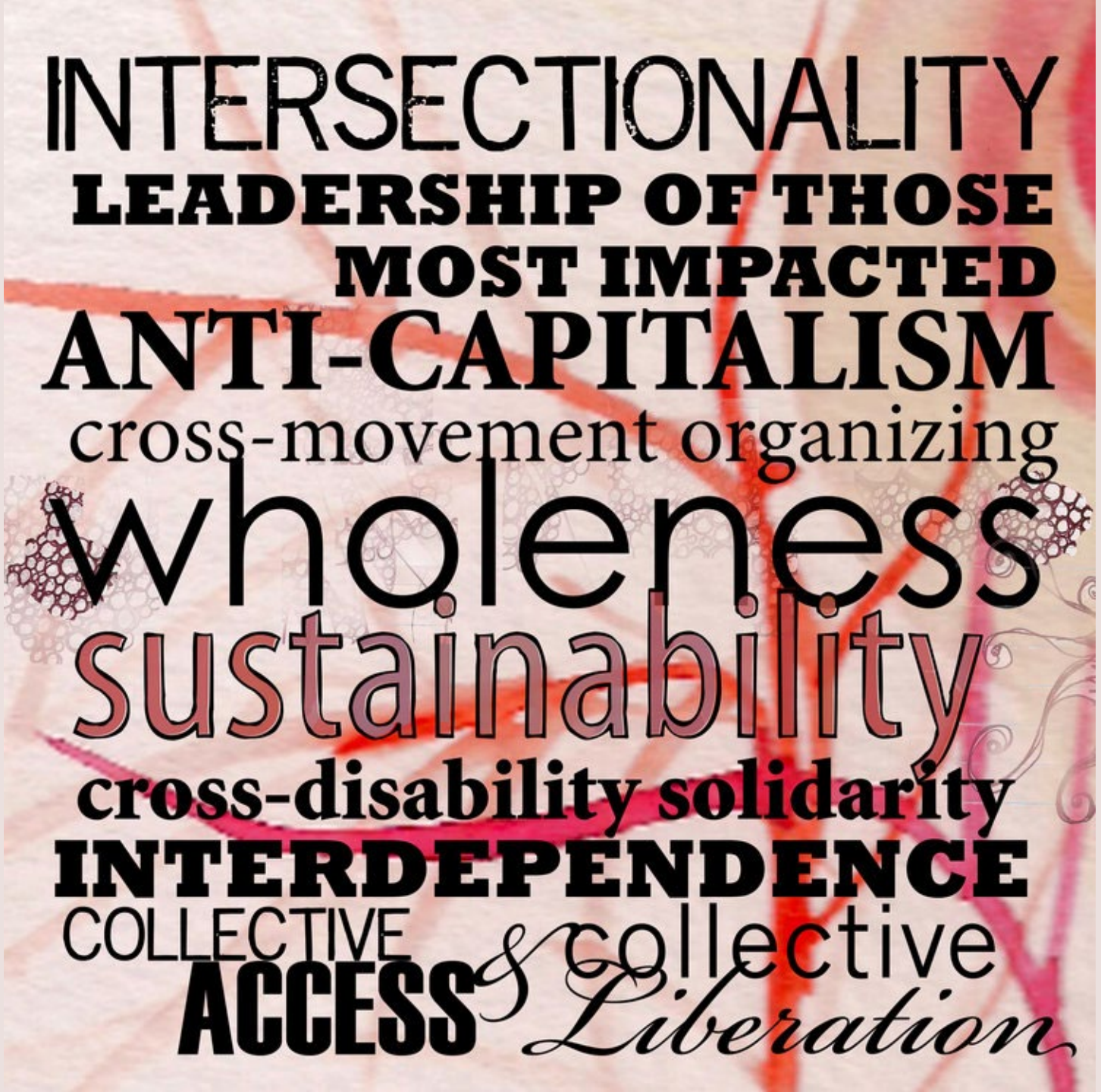
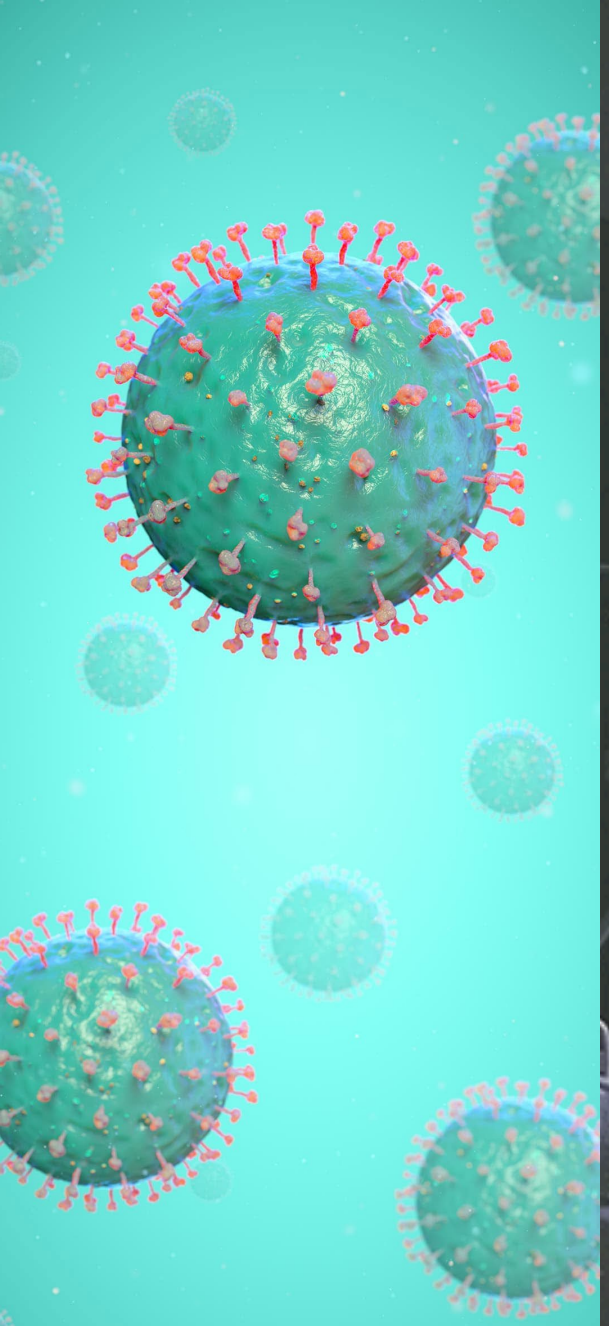

INTERSECTIONALITY
LEADERSHIP OF THOSE MOST IMPACTED
ANTI-CAPITALISM
cross-movement organizing
wholeness
sustainability
cross-disability solidarity
INTERDEPENDENCE
COLLECTIVE ACCESS & collective Liberation



March 2020

Oregon Crisis Care Guidance

Current version, June 2018

June 2018 Guidance

A MODEL APPROACH TO ALLOCATION OF SCARCE RESOURCES IN CRISIS CARE

Adapted with Oregon Crisis Care Guidance, 2018 | Version 5.1 | 2020.05.15

OVERVIEW. This is a model approach to the allocation of scarce resources in the setting of the COVID-19 pandemic if and when a surge of patients overwhelms capacity. What follows articulates crisis standards of care, including triage decision-making, for use in the COVID-19 pandemic. It was developed through an iterative and collaborative effort by clinicians, ethicists, and public health leaders based on the Oregon Crisis Care Guidance (and subsequent input from the Oregon Crisis Care Guidance Ethics Workgroup), Washington State Scarce Resource Management and Crisis Standards of Care, and National Academy of Medicine guidance. This model is intended to provide a consistent approach for local health care organizations to use in their communities if a crisis stage occurs.

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June 2018 Guidance

Oregon's Crisis Care Guidance

- Oregon Crisis Care Guidance was updated in 2018 to offer statewide guidance in major disasters and scarce resource allocation.
- The Crisis Care Community Ethics Task Force was a regional workgroup convened by Multnomah County in early 2020 that included medical ethicists and critical care providers.
- The purpose of this group was to review and adapt principles from Oregon's 2018 Crisis Care Guidelines into a regional crisis care guidance tool that Oregon hospital systems could use in case of COVID-19 surge to prioritize care.
- This group consulted with the MCPHAB Ethics Committee for input.

DRO Disability Rights Oregon | ACLU Oregon | FACTOregon Empowering families experiencing disability. | OSAC Oregon Self Advocacy Coalition

March 31, 2020

The Honorable Kate Brown
Governor of Oregon
900 Court St NE
Salem, OR 97301

Re: Addressing the needs of people with disabilities in this public health crisis

Dear Governor Brown,

Thank you and the many state agency leaders for efforts that you have collectively undertaken to provide leadership and mobilize state resources to confront the COVID-19 pandemic.

Disability Rights Oregon (DRO), the ACLU of Oregon, FACT Oregon, Oregon Self Advocacy Coalition, Oregon Council on Developmental Disabilities, and others have been diligently working with key stakeholders and governmental agencies including the Oregon Department of Developmental Services, Oregon Department of Corrections, Adults and Persons with Disabilities, Oregon Health Authority, Oregon Department of Education, the Oregon State Sheriff Association, local courts, and many local jails. *See* enclosures. We are also working closely with organizations that represent the interests of historically marginalized and oppressed communities so that we collectively can ensure clarity to our constituents to mitigate the confusion and the harm this pandemic may have on the most vulnerable in our communities.

In full recognition of your exemplary work under enormous pressure, we urge you to take additional actions that are needed to protect the welfare and self-determination of Oregonians with disabilities as the crisis evolves. We know that this public health emergency can pose an enormous challenge to the 950,000 Oregonians with disabilities who live in every corner of our state. People with disabilities are among those at the greatest risk during this crisis because of several factors including: being more likely to have underlying health conditions, being economically disadvantaged, being dependent on others for care, or simply because people with disabilities are disproportionally placed in institutions, incarcerated, or homeless. **Now is a critical time to fight so that Oregonians have equal access to the supports they need to be healthy, safe, and independent.**

Below you will find a list of responsive actions that we respectfully request for you to

March 31, 2020 Letter

Inclusive Crisis Response

1. **Include people with disabilities in response.** Like natural disasters, public health emergencies can be even worse for people with disabilities. Yet, their voices are often left out of the planning, response, and key decision-making. People with disabilities are the most effective advocates for issues that affect our lives. We need a seat at the table. Direct local government bodies and department heads to include people with disabilities and disability experts at all levels of government planning and response to address the needs of individuals with disabilities in the planning process.

April 2020 - Partners Unite

Usual Suspects:

- Oregon Council on Developmental Disabilities
- ARC of Oregon
- American Civil Liberties Union of Oregon
- Independent Living Centers

New Partners:

- Multnomah County Public Health Advisory Board (MC PHAB)
- Coalition of Communities of Color
- Native American Youth and Family Center
- Latino Network
- United Seniors of Oregon

Old Adversaries:

- State Administrators
- Hospital Ethicists

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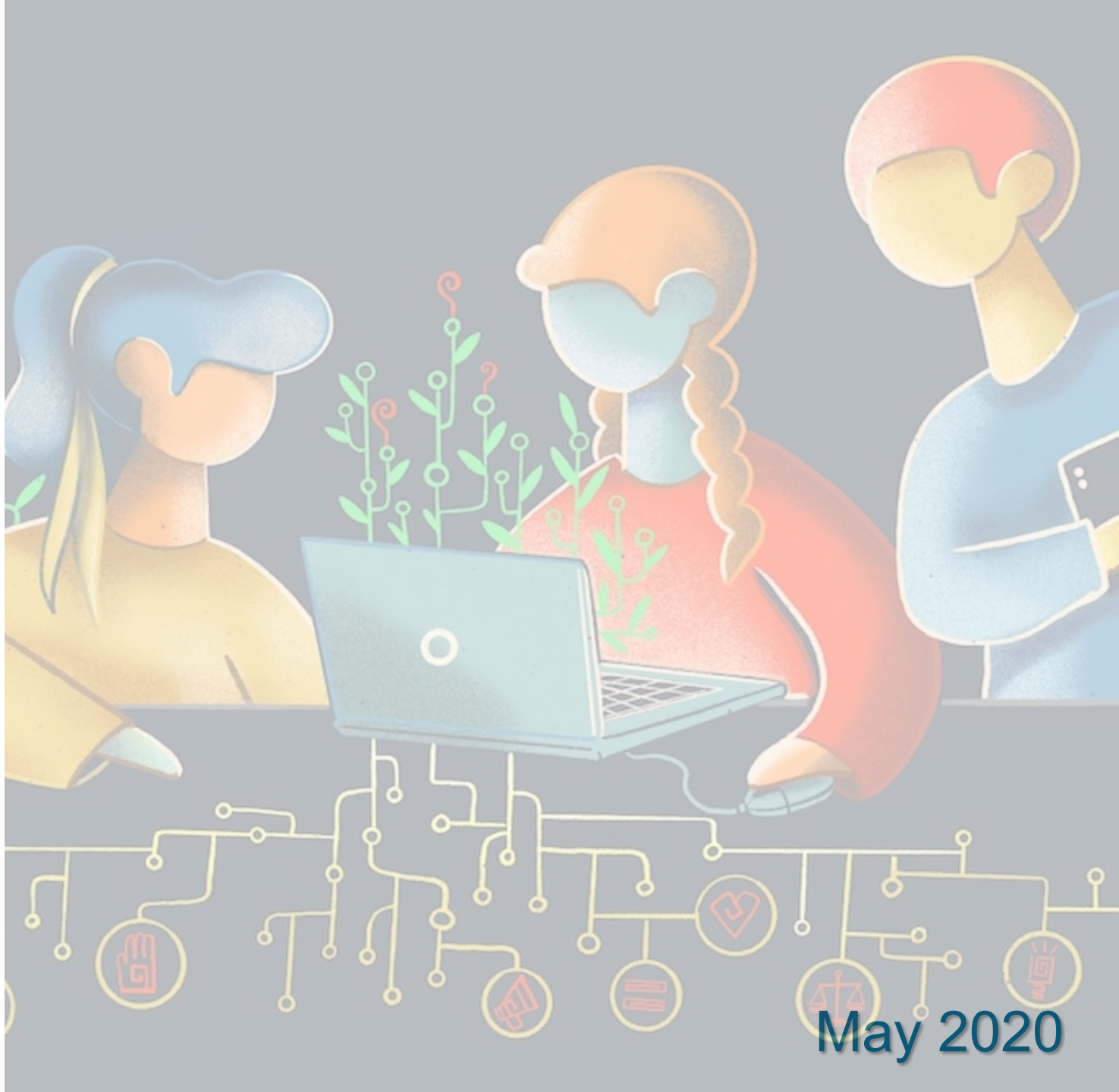
Organizing / sharing information ramps up

- Started weekly COVID-19 Advocacy calls (now bi-monthly)
- Drafted multiple letters including Health and Human Services - Office for Civil Rights complaint
- Strategized together
- Worked on policy
- Provided input to final guidance



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May 2020

Opinion

Opinion: Racist rubric underlies COVID-19 care guidelines

Published: Jul. 26, 2020, 6:00 a.m.

(AP Photo/Damian Dovarganes, File) AP AP

By Guest Columnist | The Oregonian

Ryan Petteway, Alyshia Macaysa, and Joannie Tang

Petteway, Macaysa and Tang are members of the Multnomah County Public Health Advisory Board.

COVID-19 has laid bare a true American pathology: unapologetic, litigiously defended structural racism. We've

July 26, 2020 Op-Ed

Impact of Organizing
MCPHAB Op-Ed

The Op-Ed breaks open the conversations around scarce-resource allocation that were happening behind closed doors, into the public sphere.

Community coalitions already organizing due to the advent of the COVID-19 pandemic, including those experiencing disproportionate impacts, weigh in.

This captures the attention of Oregon State leadership and the Oregon Health Authority (OHA).

September 2020, OHA announces its decision to scrap the Oregon 2018 Crisis Care Guidelines.

December 2020, OHA releases an interim statement.

December 2020 Interim Statement Outlining Principles

II. Key Principles

When allocating scarce critical resources in the face of a public health crisis, such as a surge in patients requiring hospital level of care during the COVID-19 pandemic, the key principles of ***non-discrimination, health equity***, ***patient-led decision-making***, and ***transparent communication*** should be applied.

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Key Principle	Change	Application
Non-Discrimination	Barring discrimination against protected classes is not enough. Crisis care must consider longstanding systemic racism and health inequities that have contributed to poorer health for BIPOC and people with disabilities.	Do not exclude patients on the basis of co-morbidity, underlying conditions, disability, or clinician-perceived quality of life. Triage members should be separate from clinical care team and should have expertise in antiracism and equity principles. If patients have identical triage scores, randomize.
Health Equity	Scraps traditional crisis care guidance – specifically the principle of saving the most lives or the most life-years. This systematically disadvantages BIPOC and people with disabilities and ignores historical and current health inequities.	Do not use life expectancy criterion such as 1 or 5-year mortality assessments. Use the best available medical information to assess patient short-term prognosis in terms of likelihood of surviving their current illness to hospital discharge. Do not consider resource utilization nor baseline need for ventilator when allocating scarce resources.
Patient-led Decision Making	Patients must be able to partner with their care team in making decisions. Patient care, treatment preferences, decision making support needs, and communication must be considered during scarce resource allocation.	New state law establishes that patients may have accompanying support persons to provide communication, decision making, or physical support, even during a pandemic. At least three support persons are allowed to be designated, with at least one support person to be present at all times with the patient at the hospital.
Transparent Communication	Public and patients should be informed when crisis care plans are activated, what they are, and include how resources will be allocated differently than from conventional care plans.	Communication should be timely and provided in a culturally responsive and linguistically accessible manner and meet the needs of individuals with intellectual, developmental or other disabilities.

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Know Your Rights

COVID-19 & Reasonable Accommodations in Hospitals

Updated: May 12, 2020

This guide gives general information about your rights to accommodations in hospitals during the COVID-19 pandemic. People with disabilities who go to the hospital or another medical facility may need help and support with their care, communication and managing healthcare decisions. This help or "accommodations" gives them equal access to care.

Every healthcare provider in the state must accommodate people with disabilities. During the COVID-19 pandemic, the need for proper accommodations is even more important so that people with disabilities can safely have their healthcare needs met during this emergency.

Hospitals Must Allow Individuals Who Provide Support to Patients

Early 2020 Publication

Impact of Organizing
Oregon Senate Bill 1606 (2020 Special Session)

VISITOR

- Hospitals must allow a patient to designate at a minimum 3 support persons
- Help with medical decisions
- ADLs

POLST/DNR

- No coercion
- Patients don't have to sign forms about end of life care
- Still best practice to inform & support patients who wish to engage

ADA

- Modifications
- Accommodations
- Applies to all hospital policies

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Impact of Organizing **Sharing information among Protection & Advocacy systems**

Accessibility Options | Log Out

TASC Training & Advocacy Support Center

Topic | P&A Function | Role | Resource | Discussion Forums | About TASC | Events

COVID Central

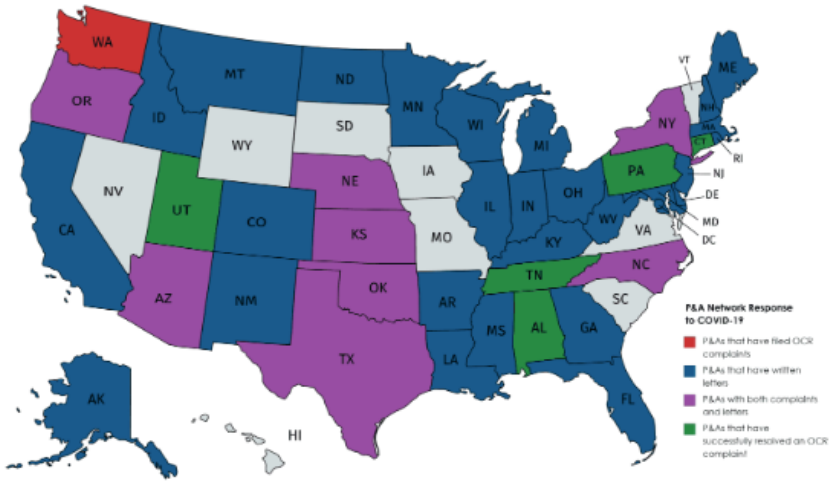
COVID Central is designed to provide timely information on P&A/CAP network SPECIFIC responses to the Coronavirus Pandemic. These quick highlights will feature creative interventions and collective concerns as we continue to receive P&A insights. Through these updates, we hope to keep the network informed, inspired and involved during the Coronavirus pandemic.

If your P&A has an effective strategy/suggestion related to monitoring, investigations, representative payee activities or any other approaches implemented by your P&A to protect disability rights in relation to COVID-19, please contact Justine "Justice" Shorter, Disaster Protection Advisor by phone at (202) 880-2435 or by email at justine.shorter@ndrn.org.

Check out these virtual events related to the Coronavirus response:

DAILY CALLS: **Partnership for Inclusive Disaster Strategies COVID-19 Disability Rights Calls**

P&A Network Response to Medical Rationing



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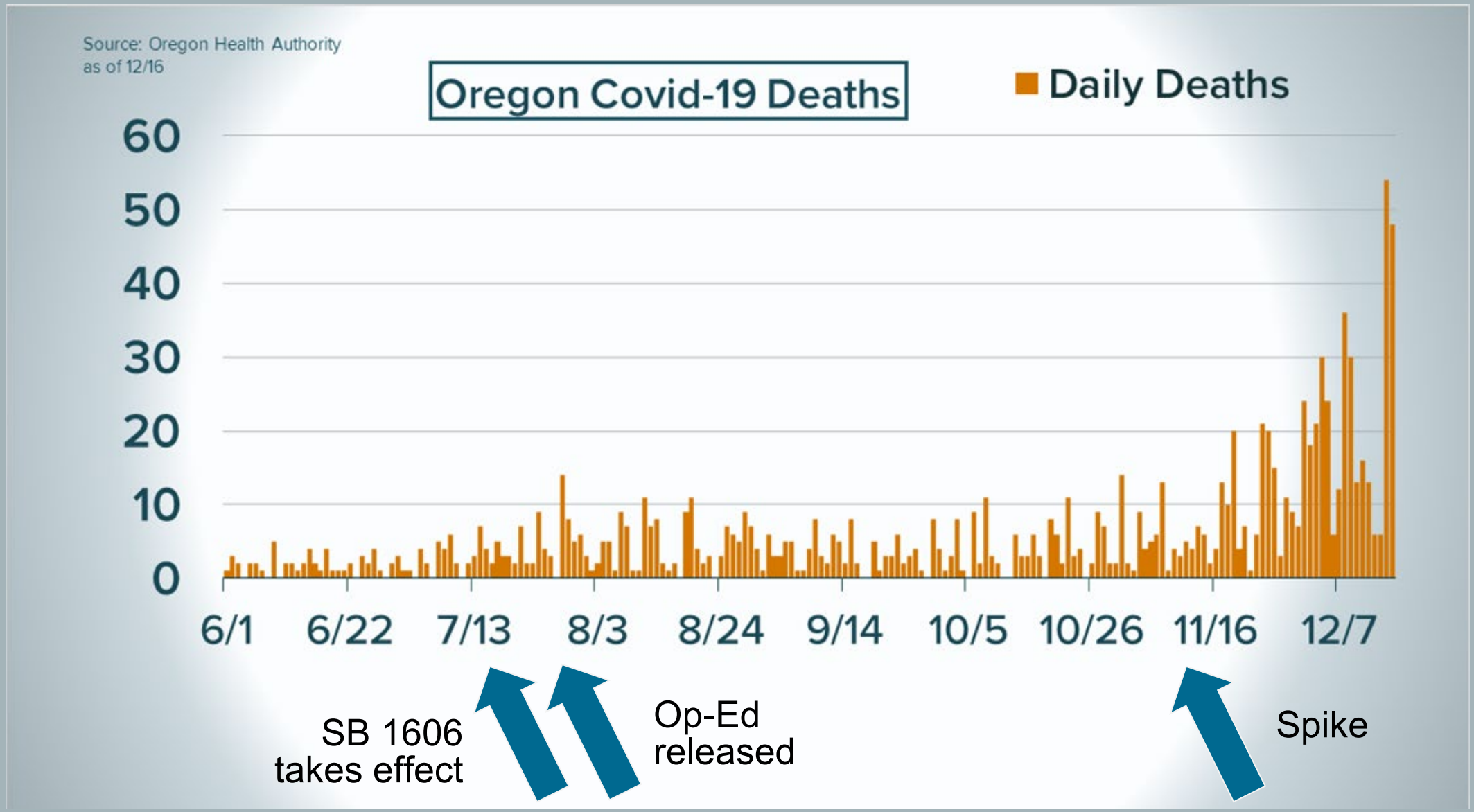
Source: Oregon Health Authority
as of 12/16
Oregon Covid-19 Deaths
Daily Deaths
60
50
40
30
20
10
0
6/1
6/22
7/13
8/3
8/24
9/14
10/5
10/26
11/16
12/7
SB 1606
takes effect
Op-Ed
released
Spike

What's Next?

Still work to do on allocation principles:

- Permanent
- Inclusive
- Transparent
- Fair

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OFFICE OF THE DIRECTOR
Kate Brown, Governor

Oregon Health Authority

500 Summer St NE E20
Salem OR 97301
Voice: 503-947-2340
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January 7, 2022

Oregon Interim Crisis Care Tool

Principles

In the event of a public health crisis, healthcare demands may overwhelm available capacity to offer potentially life-saving care to all who need it. With an expected Omicron surge ahead which will further overwhelm hospital capacity, OHA is issuing this interim crisis care tool that hospitals can use to equitably prioritize care in the face of limited intensive care beds, ventilators and other life-saving resources should it be needed.

OHA developed this interim crisis care tool based on several existing triage tools, such as those published by Arizona, Massachusetts and Washington, and made adaptations according to Oregon's Principles in Promoting Health Equity in Resource Constrained Events.[1] These principles include non-discrimination, health equity, patient-led decision making and transparent communications.

Oregon hospitals may activate crisis standards of care if their critical care resources are severely limited, the number of patients presenting for critical care exceeds capacity, and there is no option to transfer patients to other critical care facilities.

For hospitals with an existing crisis care tool relating to scarce critical care resources, they may continue to use the existing tool so long as it is consistent with the principles outlined in Principles in Promoting Health Equity in Resource Constrained Events and does not violate state or federal anti-discrimination laws, or any other applicable laws.

The Omicron surge does not allow time for the robust, comprehensive and fully inclusive community and clinician engagement needed to establish a more permanent triage tool for Oregon hospitals. OHA remains committed to urgently continuing our parallel work to co-create new tools for the allocation of scarce resource with our community partners and healthcare providers in Oregon, and will convene the new Oregon Resource Allocation Advisory Committee this winter. This committee will inform revisions to OHA's 2020 published principles and this interim crisis care tool and guide the development of any additional necessary resources that help to center health equity in processes and decisions when healthcare system


Thank
you