



**TO:** Senate President Peter Courtney; House Speaker Tina Kotek; Senate Republican Leader Fred Girod; House Republican Leader Christine Drazen; & Members of the Joint Interim Committee on the First Special Session of 2020  
**FROM:** Disability Rights Oregon  
**DATE:** June 22, 2020  
**RE:** Support for Legislative Concept 52

Chair and Members of the Committee:

Thank you for your efforts to safeguard Oregonians during a worldwide pandemic. I write in support of Legislative Concept 52.

Since the beginning of this public health crisis, Disability Rights Oregon has seen a steady stream of substantiated complaints of discrimination and bias in the health care system and denial of rights of people with disabilities, older adults, and people of color. These complaints are widespread, coming from every corner of the State and from nearly every hospital system. This has already resulted in substandard care and the premature death of people with disabilities. This is an urgent problem that must be addressed during this legislative session.

#### **ABOUT DISABILITY RIGHTS OREGON**

Disability Rights Oregon is a statewide nonprofit that upholds the civil rights of 950,000 people with disabilities in Oregon to live, work, and engage in the community. Disability Rights Oregon serves as a watchdog over state agencies and institutions as we work to transform systems, policies, and practices to give more people the opportunity to reach their full potential. For more than 40 years, the organization has served as Oregon’s federally authorized and mandated Protection & Advocacy System. Disability Rights Oregon is committed to ensuring the civil rights of all people are protected and enforced, including in healthcare settings during the pandemic.

#### **DISCRIMINATION AND BIAS IN HEALTHCARE HAS OCCURRED, AND CONTINUES**

Since the beginning of this health crisis, Disability Rights Oregon has received a steady stream of substantiated complaints of discrimination and bias in the health care system. While I am not able to share details of every individual case due to confidentiality requirements, I want to highlight a few examples of the complaints we are receiving.

- In March, Disability Rights Oregon investigated and substantiated a complaint about a person with an intellectual disability with COVID-19 being inappropriately influenced about regarding life sustaining medical treatment. The physician cited the “low quality of life” of the person with a disability.

- In April, Disability Rights Oregon investigated another complaint, this time made by a physician—at yet another hospital. The hospital denied a patient with disabilities her request to either visitation by her Personal Care Attendant, family, or to have the hospital provide the hourly, intermittent care services she needs to remain safe. The hospital denied this over the objections of the physician overseeing treatment.
- In May, we investigated another complaint—at yet another hospital—of a patient being denied her request for the hospital to modify policies. Policy modification was necessary to permit the patient to communicate with hospital personnel and receive regular care. We worked with National Public Radio to share this client’s experience.<sup>1</sup>
- In June, while the number of new cases was in decline, we continued to receive complaints about discrimination against people with disabilities seeking care, even in counties that are “opening up.”
- Today, we continue to investigate the case of Sarah McSweeney. Sarah was a 45-year-old woman who loved going out to coffee and taking trips with friends. She also loved getting her hair done, listening to music, and was looking for a job. On April 21, 2020, she went to Providence Hospital with a slight fever. From the very first day of her hospital stay, hospital staff repeatedly pressed her guardian to sign a Do Not Resuscitate Order. It was clear to Sarah’s guardian and care team that the hospital did not believe she lived a quality life based on her disabilities. When Sarah’s team tried to explain to the hospital that Sarah lived a very full and promising life, the hospital staff replied in a sarcastic and surprised manner, “this girl?” Sarah died on May 10, 2020. Hospital records reveal that she was in distress in the days and hours leading up to her death. Disability Rights Oregon is continuing to investigate the circumstances around Sarah’s death.
- We continue to learn of people with intellectual and developmental disabilities who are getting sick and dying in group homes.<sup>2</sup>

Complaints have come from every corner of our state and from nearly every hospital system. The reality many of us in the disability community live with every day is that our lives will simply not be valued and will not be saved.

The fact that bias and discriminatory healthcare rationing is occurring—in the absence of a shortage of providers or equipment—leaves Oregonians with disabilities with great fear about how decisions will be made if rationing becomes necessary later in the year.

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<sup>1</sup> NPR, “Hospital Visitor Bans Under Scrutiny After Disability Groups Raise Concerns Over Care”, [May 17, 2020](#).

<sup>2</sup> The Oregonian, “2 men from group homes for people with disabilities dead from coronavirus as advocates point to problems”, [June 18, 2020](#).

## **OREGON'S CRISIS CARE GUIDE: PLAN TO RATION HEALTHCARE**

In Oregon, the State has a plan for how it will ration health care if that becomes necessary because of COVID-19. This plan is called the Crisis Care Guide.<sup>3</sup> If health care rationing becomes necessary, this Guide will dictate who gets care and who doesn't.

When Disability Rights Oregon's attorneys dug into what that plan includes, it is highly problematic. Rather than dwelling on the problems with this State Guide—which are many—I would direct you to the complaint sent to the Federal Office for Civil Rights.<sup>4</sup> A coalition of 20 organizations representing people of color, older adults, and people with disabilities joined this complaint. The Oregon Health Authority must revise this document based on a few key principles:

- First, no person should be disqualified from receiving critical care solely on the basis of their disability, race, age, or other protected class.
- Second, stereotypes, assessments of quality or quantity of life, judgments about a person's "worth", and bias in decision-making based on the presence or absence of disabilities cannot be tolerated. This includes using expected number of life years, life expectancy, or long-term survivability in decision making, which have the result of discriminating against people with disabilities and people of color who have long suffered inequity in the health care system.
- Third, reasonable modifications to policies must be made to provide equal opportunity to healthcare, including allowing visitors to support people with disabilities.

## **VOICES OF PEOPLE WITH DISABILITIES IN OREGON**

Disability Rights Oregon reached out to our community, asking folks to tell us why they are concerned about discrimination in healthcare. More than 200 people from every corner of the state wrote urging the Legislature to prohibit discrimination in healthcare rationing based on protected characteristics.

We wanted to highlight for you a few of the response we received.

- Jenny from Eugene said: "disabled people are already discriminated against enough in healthcare settings."
- Roger, from Eugene said: "I am concerned because I am experiencing my white peers getting testing during this pandemic yet the disabled people of color being denied."

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<sup>3</sup> Oregon Crisis Care Guidance Providing a Framework for Crisis Health Care, [June 2018](#).

<sup>4</sup> *Letter to Roger Severino, Director of the Office for Civil Rights at the U.S. Department of Health and Human Services*, [May 8, 2020](#).

- Laura, in Portland, wrote: “I have a child who experiences a disability. He should be afforded equal access to healthcare as his non-disabled peers.”
- Amy from Eugene wrote: “Disabled Oregonians have value. My daughter has value. Lives should not be rationed.”
- Kevin from Portland wrote: "It's 30 years after passage of the Americans with Disabilities Act. Unfortunately, the COVID-19 crisis makes it clear that healthcare (and other) institutions will not meet their obligation for equal treatment of the disabled without aggressive action by the Legislature.”

Disability Rights Oregon urges the Legislature to introduce and enact Legislative Concept 52 to make clear that discrimination in healthcare will not be tolerated, especially during a crisis.

### **DISABILITY RIGHTS OREGON’S REQUESTS**

Now that a Special Session is being convened, Disability Rights Oregon requests the Legislature to introduce and enact Legislative Concept 52, which:

- Prohibits discrimination in the provision of healthcare, consistent with Federal requirements under Title II of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, Section 1557 of the Patient Protection and Affordable Care Act, the Civil Rights Act of 1964, Age Discrimination Act of 1975, and several further provisions of law, including under the Public Health Service Act.
- Requires hospitals to permit support workers for people with disabilities to provide services in hospital settings, which are frequently necessary for communication and activities of daily living. This underscores the importance of healthcare systems to comply with the Americans with Disabilities Act, including reasonable modifications in policies.
- Makes clear that healthcare cannot be conditioned on agreeing to the withholding of life sustaining care and requires that Disability Rights Oregon be notified in certain cases of the proposed withholding or withdrawing of life-sustaining procedures.

In addition to the issues addressed by Legislative Concept 52, we look forward to working with the medical community in the coming months to discuss how end-of-life care should be improved in order to further address concerns about inappropriate coercion of people with disabilities. We hope this work will yield solutions for the legislature to consider in 2021, however, the solutions in Legislative Concept 52 must be urgently enacted to save the lives and safeguard the liberties of people with disabilities.

Disability Rights Oregon stands ready to work with you in these efforts.