

June 20, 2020

Paul Terdal  
Resident, NW Portland / SD18 / HD36  
Founder, "Autism Insurance for Oregon"

Joint Interim Committee On The First Special Session of 2020  
Oregon State Capital  
980 Court Street  
Salem, Oregon 97301

Re: Support for LC52: Guaranteeing Access to Appropriate Lifesaving Testing, Care and Treatment for Higher Risk Populations

Dear Senate President Courtney, Speaker Kotek, and members of the committee,

I'm writing in support of Senator Gelser's LC52, which would guarantee access to appropriate lifesaving testing, care, and treatment for higher risk populations.

In the past few months, there have been newspaper Op Eds explicitly calling for discriminatory rationing policies that would deny life saving care to individuals on the basis of disability or age – despite the fact that such policies would violate Federal law (including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act, and the Age Discrimination Act) and the Equal Protection clause of the 14<sup>th</sup> Amendment to the U.S. Constitution.

Last month, I joined over 430 state and national organizations representing patients, people with disabilities and older adults urging the U.S. Department of Health and Human Services to issue additional guidance to ensure that schemes to ration scarce health care resources during the coronavirus disease 2019 (COVID-19) pandemic comply with federal nondiscrimination laws (see attached).

Here in Oregon, the patient advocacy community has been asking the State to issue clear and specific guidance protecting the rights of Oregonians with disabilities and older adults against discrimination – without success. As [Disability Rights Oregon has described in written testimony to the House Health Care committee last month](#), discrimination is happening now, here in Oregon:

- Intellectually disabled patients with COVID-19 have been pressured into signing Do Not Resuscitate / Do Not Intubate orders that they do not understand, based on the Physician's belief in their "low quality of life."
- Other individuals with disabilities have been denied access to caregivers, even when necessary to support communication needs essential to provide informed consent and participate in care, in violation of the Americans with Disabilities Act.

I urge this committee to join Senator Gelser and the patient advocacy to clearly state Oregon's policy against healthcare discrimination on the basis of disability, age, or race.

Sincerely,

/s

Paul Terdal

Autism Insurance for Oregon

**Enclosure:**

- Advocate letter to Secretary Azar and Director Severino supporting nondiscrimination, 4/16/2020

April 16, 2020

The Honorable Alex Azar  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue S.W.  
Washington, DC 20201

Roger Severino  
Director  
Office for Civil Rights  
U.S. Department of Health and Human Services  
200 Independence Avenue S.W.  
Washington, DC 20201

Dear Secretary Azar and Director Severino:

Representing millions of patients, people with disabilities and older adults, our organizations are writing to express our strong and urgent support for the Department's Office for Civil Rights to issue additional guidance to ensure that schemes to ration scarce health care resources during the coronavirus disease 2019 (COVID-19) pandemic comply with federal nondiscrimination laws.

As you are aware, many states and hospitals plan to rely on Crisis Standard of Care plans to inform providers how to make decisions on the allocation and re-allocation of scarce medical resources. Too many of these plans, however, discriminate based on disability and age, devaluing the lives of people with disabilities and older adults. If implemented, they would deny life-saving treatment to people based on disabilities or age that have nothing to do with their ability to benefit from care and survive COVID-19. This violates the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act, and the Age Discrimination Act.

It is essential that the federal government provide guidance to states and health care providers setting forth clear requirements to ensure that the health care rationing decisions comply with federal nondiscrimination laws. We greatly appreciate the guidance that has already been issued by the Office of Civil Rights (OCR) in its March 28, 2020 bulletin. But significant confusion remains in the health care provider community. As states move forward with rationing plans in the face of imminent shortages of ventilators and other supplies, hospital beds, and staff, it is urgent that you issue additional guidance.

Additional guidance should clarify that federal law prohibits treatment allocation decisions from being made based on assumptions that a person's disability or age will diminish the person's prospect of survival beyond the immediate term or require the use of greater treatment resources. It should clarify that allocation decisions based on "life years," life expectancy, or

prognosis beyond short-term survival discriminate against disabled people and older adults. It should clarify that reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment. These may include interpreter services, modifications such as increased baseline times for responsiveness to treatment, or additional services needed due to a disability.<sup>1</sup> Similarly, OCR guidance should clarify that federal law prohibits age-based categorizations that penalize older adults by making them automatically ineligible for life-saving care without any individualized assessment.

We agree with the National Council on Disability, which urged OCR to issue clear guidance on these issues and “to maintain robust enforcement activities, including investigations of complaints, and to remind the public in every one of OCR’s communications how they can file such complaints,” and recommended that HHS, “at every opportunity and through each one of its divisions and offices, include standardized language in each of its communications, no matter the topic, regarding civil rights obligations and the steps by which an individual may file a complaint if they believe their civil rights have been violated.”<sup>2</sup>

We also strongly recommend that OCR advise states and healthcare entities of their obligation to maintain data concerning the administration of health care rationing, including accurate tracking of the numbers of persons admitted to hospital, the number who receive ICU for COVID-19 treatment, the number who are denied care or transferred to palliative care only, the number who recover, and the number who die, including disaggregated information about these individuals’ racial, ethnic, gender, and disability status, and whether they were receiving life-sustaining care or palliative care only based on rationing at time of death. Lives have been and will be lost to COVID-19. We owe it to those lives to learn how to better our society and healthcare system’s response to a pandemic, and we cannot achieve improvement without accurate data.

We are pleased that Congress shared its intent that civil rights laws be upheld in this crisis in a bipartisan and bicameral manner in a March 25, 2020 letter to Secretary Azar and Attorney General Barr, stating:

In light of the COVID-19 pandemic, we urge your Department to act quickly to notify states that as they review and create their "crisis standards of care," they must not authorize or promote any form of disability discrimination that would violate the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. This would include incorporating denials of care, lower prioritization of care, or denial of or limitation of

---

<sup>1</sup> See Letter of March 20, 2020 from Consortium for Citizens with Disabilities Rights and Health Task Force Co-Chairs to Secretary Azar and Director Severino, <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>.

<sup>2</sup> <https://ncd.gov/publications/2020/NCD-letter-response-ocr-bulletin-civil-rights-hipaa>.

healthcare resources on the basis of one's disability, severity of disability, need for resource-intensive services and supports, or the perception of a lower quality of life on the basis of disability.<sup>3</sup>

The policies and guidelines in a significant number of states deny or give lower priority for life-saving treatment to the people with disabilities and older adults that we represent, including those that are the subject of complaints filed with OCR.<sup>4</sup> Policies across the country give people with disabilities and older adults good cause for alarm.<sup>5</sup> We rely on you and your leadership to ensure that the United States lives up to its promise of equal opportunity, nondiscrimination and civil rights of all human beings, especially during times of crisis. Therefore, we look forward to your further guidance and continued enforcement of our civil rights laws.

Sincerely,

### **National Organizations**

ACCSES

ACORN8

African Services Committee

Aging Life Care Association

Albie Aware Breast Cancer Foundation

Alliance for Aging Research

Allies for Independence

ALPHA-1 FOUNDATION

ALS Association

American Academy of Physical Medicine & Rehabilitation

American Association of People with Disabilities

American Association on Health and Disability

---

<sup>3</sup> [https://chrissmith.house.gov/uploadedfiles/2020-03-25\\_bipartisan\\_bicameral\\_letter\\_to\\_hhs\\_and\\_doj\\_-\\_covid-19\\_and\\_disability\\_discrimination.pdf](https://chrissmith.house.gov/uploadedfiles/2020-03-25_bipartisan_bicameral_letter_to_hhs_and_doj_-_covid-19_and_disability_discrimination.pdf). A number of Senators sent a second letter on April 9, 2020 reiterating this view.

<https://www.warren.senate.gov/imo/media/doc/2020.04.09%20Letter%20to%20HHS%20OCR%20re%20Rationing%20of%20Care.pdf>.

<sup>4</sup> <https://www.centerforpublicrep.org/covid-19-medical-rationing/>.

<sup>5</sup> <https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators>.

American Association of Kidney Patients  
American Autoimmune Related Diseases Association  
American Behcet's Disease Association  
American Congress of Rehabilitation Medicine  
American Council of the Blind  
American Geriatrics Society  
American Kidney Fund  
American Music Therapy Association  
American Music Therapy Association  
American Network of Community Options & Resources (ANCOR)  
American Physical Therapy Association  
American Psychological Association  
American Therapeutic Recreation Association  
Association of Academic Physiatrists  
Association of Programs for Rural Independent Living  
Association of University Centers on Disabilities (AUCD)  
Asthma and Allergy Foundation of America  
Autism Society of America  
Autistic Self Advocacy Network  
Autistic Women & Nonbinary Network  
Autistic Women and Nonbinary Network  
Axis Advocacy  
Bazelon Center for Mental Health Law  
Black AIDS Institute  
Bloom's Connect  
Brain Injury Association of America

Bridge the Gap - SYNGAP Education and Research Foundation

California Chronic Care Coalition

Cancer and Careers

Cancer Support Community

CancerCare

Caregiver Action Network

Center for Autism and Related Disorders

Center for Disability Rights

Center for Independence

Center for Public Representation

CFC International

Christopher & Dana Reeve Foundation

Chronic Care Policy Alliance

Chronic Disease Coalition

Civil Rights Education and Enforcement Center

Coelho Center for Disability Law, Policy and Innovation

CommunicationFIRST

Community Access Center

Community Options, Inc.

COPD Foundation

Cure SMA

cutaneous lymphoma foundation

Cystic Fibrosis Lifestyle Foundation

Cystic Fibrosis Research, Inc. (CFRI)

Davis Phinney Foundation

Depression and Bipolar Support Alliance

Diabetes Patient Advocacy Coalition (DPAC)

Disability Action for America

Disability:IN

Disability Justice

Disability Law Center

Disability Power & Pride

Disability Resource Center

Disability Rights Advocates

Disability Rights Education and Defense Fund

Down Syndrome Affiliates in Action

Dreamsickle Kids Foundation

Easterseals

Epilepsy Foundation

EveryLife Foundation for Rare Diseases

Friends of Cancer Research

Global Liver Institute

GO2 Foundation for Lung Cancer

Healthcare Rights Coalition

Heart Valve Voice US

Hepatitis Education Project

HIGH IMPACT Mission-based Consulting & Training

Huntington's Disease Society of America

Immune Deficiency Foundation

Independence Empowerment Center

Independent Lifestyles, Inc.

International Foundation for Autoimmune & Autoinflammatory Arthritis



Justice in Aging

Lakeshore Foundation

Linking Employment, Abilities and Potential (LEAP)

Little Lobbyists

Living Beyond Breast Cancer

Livpact

LUNgevity Foundation

Lupus and Allied Diseases Association, Inc.

Lutheran Services in America

Medicare Rights Center

Men's Health Network

Mental Health America

MLD Foundation

Multiple Sclerosis Foundaiton

Muscular Dystrophy Association

NASTAD

National Academy of Elder Law Attorneys

National ADAPT

National Alliance for Hispanic Health

National Alliance on Mental Illness

National Assocation of Councils on Developmental Disabilities

National Association of Rehabilitation Research and Training Centers

National Association of Social Workers (NASW)

National Association of State Directors of Developmental Disabilities Services

National Association of State Head Injury Administrators

National Center for Learning Disabilities

National Center for Transgender Equality

National Coalition for LGBT Health

National Council on Independent Living

National Diabetes Volunteer Leadership Council

National Disability Rights Network

National Down Syndrome Congress

National Health Council

National Health Law Program

National Hemophilia Foundation

National Infusion Center Association

National Minority Quality Forum

National MPS Society

National Multiple Sclerosis Society

National Organization for Rare Disorders

National Pain Advocacy Center

National Respite Coalition

National Sickle Cell Disease Association of America

Native American Disability Law Center

NCMHR

NMD United, Inc.

Not Dead Yet

NTM Info & Research

Paralyzed Veterans of America

Parent Project Muscular Dystrophy

Partnership for Inclusive Disaster Strategies

Partnership to Fight Chronic Disease

Partnership to Improve Patient Care  
Patient Advisor  
Patient Services Inc.  
Pulmonary Hypertension Association  
Rare Army  
RASopathies Network  
Resource Center for Accessible Living  
RespectAbility  
SeniorLAW Center  
Sickle Cell Anemia Foundation  
Sickle Cell Asociation  
Sickle Cell Foundation Incorporated  
Solve ME/CFS Initiative  
Spina Bifida Association  
TASH, Inc.  
The Advocacy Institute  
The AIDS Institute  
The Arc of the United States  
The Bonnell Foundation: Living with cystic fibrosis  
The Center for HIV Law and Policy  
The Center for Independence of Individuals with a Disabilities  
The Coelho Center for Disability Law, Policy and Innovation  
The Gerontological Society of America  
The Hepatitis C Mentor and Support Group-HCMSG  
The Migraine Diva  
The National Kidney Foundation

The Well Project

Treatment Action Group

U.S. Pain Foundation

United Cerebral Palsy National

United Spinal Association

United States International Council on Disabilities

VetsFirst

Whistleblowers of America

Williams Syndrome Association

Yad HaChazakah-The Jewish Disability Empowerment Center Inc.

## **State Organizations**

Ability360

Access Alaska, Inc.

Access Living

Accessible Resources for Independence Incorporated

ADAPT Montana

ADAPT of Boston

ADAPT of Texas

Aging Services Collaborative of Santa Clara County

AIDS Law Project of Pennsylvania

AIM Independent Living Center

Alabama Disabilities Advocacy Program

Alliance Center for Independence

Aloha Independent Living Hawaii

American Nurses Association\California

Arizona ADAPT

Arizona Center for Disability Law

Arizona Epilepsy Foundation

Autism Insurance for Oregon

BIAA-KY

Boston Center for Independent Living

Boston Commission for Persons with Disabilities

Brain Injury Association of Delaware

Brain Injury Association of Georgia

Brain Injury Association of Illinois

Brain Injury Association of Kansas and Greater Kansas City

Brain Injury Association of Massachusetts

Brain Injury Association of New York State

Brain Injury Association of SC

Brain Injury Association of VA

Bronx Independent Living Services

Brooklyn Center for Independence of the Disabled

CA SILC

California Access Coalition

California Disaster Strategies Coalition

California Foundation for Independent Living Centers

Cape Organization for Rights of the Disabled (CORD)

Catskill Center for Independence, Inc.

Center for Disability Rights - CT

Center for Independence of the Disabled, NY  
Center for Independent Living of Central PA  
Center for Living & Working, Inc.  
Center on Disabilities and Human Development  
Central Iowa Center for Independent Living  
Central PA ADAPT  
Community Legal Services of Philadelphia  
Community Resources for Independence  
Consortium of Idahoans with Disabilities  
Consumer Directed Personal Assistance Association of New York State  
CRIL  
DAWN Center for Independent Living  
Democratic Disability Caucus of Florida  
Designer Genes of North Dakota, Inc.  
DIRECT Center for Independence  
Disabilities Law Program of Community Legal Aid Society, Inc.  
Disabilities Resource Center of Siouxland  
Disability Action Center - NW, Inc.  
Disability Community Hub  
Disability Community Resource Center, Inc.  
Disability Empowerment Center  
Disability Law Center  
Disability Law Center of Alaska  
Disability Law Colorado  
Disability Policy Consortium  
Disability Resource Center

Disability Rights Arkansas  
Disability Rights California  
Disability Rights Center - New Hampshire  
Disability Rights Center of Kansas  
Disability Rights Florida  
Disability Rights Idaho  
Disability Rights Iowa  
Disability Rights Louisiana  
Disability Rights Maine  
Disability Rights Mississippi  
Disability Rights Montana  
Disability Rights Nebraska  
Disability Rights New Jersey  
Disability Rights North Carolina  
Disability Rights of West Virginia  
Disability Rights Ohio  
Disability Rights Oregon  
Disability Rights TN  
Disability Rights Vermont  
Disability Rights Wisconsin  
Disability:IN Greater Kansas City  
Disability:IN North Carolina  
Disability:IN Ohio  
Disabled Resources Center, Inc. (DRC)  
Down Syndrome Alliance of the Midlands  
Down Syndrome Association of Brevard

Down Syndrome Association of Connecticut  
Down Syndrome Awareness Group of East TN  
Down Syndrome Indiana  
El Paso Desert ADAPT  
ENDependence Center of Northern Virginia  
Epilepsy Fondation New England  
Epilepsy Foundation Arizona  
Epilepsy Foundation Central & South Texas  
Epilepsy Foundation Greater Los Angeles  
Epilepsy Foundation Iowa  
Epilepsy Foundation Maryland  
Epilepsy Foundation Nebraska  
Epilepsy Foundation of Colorado  
Epilepsy Foundation of Kentuckiana  
Epilepsy Foundation of Long Island  
Epilepsy Foundation of Michigan  
Epilepsy Foundation of Middle and West TN  
Epilepsy Foundation of Minnesota  
Epilepsy Foundation of Nevada  
Epilepsy Foundation of Northern California  
Epilepsy Foundation of San Diego County  
Epilepsy Foundation of Virginia  
Epilepsy Foundation Ohio  
Epilepsy Foundation Oregon  
Epilepsy Foundation Texas - Houston/Dallas-Fort Worth/West Texas  
Epilepsy Foundation Utah



Epilepsy Foundation Washington  
Epilepsy Foundation West Virginia  
Family Voices of CA  
Finger Lakes Independence Center  
Florida Association of Centers for Independent Living  
Freedom Valley Disability Enablement, Inc.  
GDC Lifespan  
Granite State Independent Living  
Gulf Coast ADAPT  
Houston Center for Independent Living  
Idaho Anti-Trafficking Coalition  
Idaho Council on Developmental Disabilities  
Idaho State Independent Living Council  
ILRCSF  
IMAGE Center of Maryland  
IndependenceFirst  
Independent Living Center of the Hudson Valley, Inc.  
Independent Living Resource Center San Francisco  
Independent Living, Inc.  
Indiana Disability Rights  
Indiana Statewide Independent Living Council  
Intermountain Fair Housing Council  
Iowa Chapter of United Spinal Association  
Iowa SILC  
Kansas ADAPT  
Lake County Center for Independent Living

Legal Clinic for the Disabled, Inc.

Life, A Center for Independent Living

LINC- Living Independence Network Corporation

Living River: A Retreat on the Cahaba

Long Island Center for Independent Living

LVCIL (Lehigh Valley Center for Independent Living, (Inc.)

Mass Families Organizing for Change

Massachusetts

MassADAPT

Metropolitan Center for Independent Living

Michigan Protection & Advocacy Service, Inc.

Minnesota Disability Law Center/Mid-Minnesota Legal Aid

Minnesota Statewide Independent Living Council

Multiple Sclerosis Foundation

Nebraska Statewide Independent Living Council

Nevada Disability Advocacy & Law Center

New York Association on Independent Living

New York Association on Independent Living

New York State Sickle Cell Advocacy Network INC, NYS.SCAN,

North Alabama Sickle Cell Foundation, Inc.

North Carolina AIDS Action Network

North Central Independent Living Services, Inc.

North Central PA ADAPT

North Dakota Protection & Advocacy Project

Northeast Independent Living Program Inc

Northern Regional Center for Independent Living, Inc.

NW ADA Center-Idaho, Idaho Access Project

NYU Law Disability Allied Law Student Association

Ocean State Center for Independent Living

Options for Independent Living, Inc.

PA ADAPT

PA Families Need Nurses Now

Paraquad

Pennsylvania Council on Independent Living

Personal Attendant Coalition of Texas

Personal Attendant Coalition of Texas

Philly ADAPT

Placer Independent Resource Services- local organization

Protection & Advocacy System, Inc.

Protection and Advocacy for People with Disabilities, Inc

Resource Center for Accessible Living, Inc.

RCIV

Roads To Freedom CIL

Roads to Independence

San Antonio ADAPT

Service Center for Independent Life

Sickle Cell Anemia Foundation or Oregon, Inc.

Sickle Cell Assoc of Houston

Sickle Cell Association - West Alabama Chapter, Inc

Sickle Cell Disease Association of America - Mobile Chapter, Inc.

Sickle Cell Disease Association of Florida

Silicon Valley Independent Living Center

SKIL Resource Center

SKIL Resource Center

Southeast Alaska Independent Living, Inc. (SAIL)

Southeastern MN Center for Independent Living

Southeastern MN Center for Independent Living, Inc.

Southern Tier ADAPT

Southern Tier Independence Center

Southwest Center for Independence

Southwest Louisiana Independence Center

Statewide Independent Living Council of Illinois

Statewide Independent Living Council of Kansas

Stavros Center for Independent Living, inc.

Taconic Resources For Independence, Inc.

Tennessee Disability Coalition

Texas State Independent Living Council

The Arc Tennessee

The Center for Disability Empowerment

The Dayle McIntosh Center

The Disability Resource Center of the Rappahannock Area, Inc.

The Independence Center

The Sickie Cell Association of Kentuckiana

The Sickie Cell Association of New Jersey

The Sickie Cell Foundation of Tennessee

Topeka Independent Living Resource Center

Tri-County Independent Living

United Vision for Idaho

Virginia Board for People with Disabilities

Vision for Equality

Washington ADAPT

West Virginia Statewide Independent Living Council

Westchester Independent Living Center

Wyoming SILC