

June 25, 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 SB1606: 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 SB1606, 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 14th 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.¹ 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.”²

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

¹ 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>.

² <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.³

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.⁴ Policies across the country give people with disabilities and older adults good cause for alarm.⁵ 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

³ 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>.

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

⁵ <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 Association 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 Association
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-HCMMSG
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 Foundation 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 Sickle Cell Association of Kentuckiana

The Sickle Cell Association of New Jersey

The Sickle 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