



800.342.1660 | www.disabilityrightstn.org | gethelp@disabilityrightstn.org

Middle Tennessee Regional Office
Administration & Legal Department
2 International Plaza, Suite 825
Nashville, TN 37217
615.298.1080 phone
615.298.2046 fax

March 27, 2020

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

RE: Complaint of Erin Brady Worsham, Jean Marie Lawrence, Toni Corbin, John and Pam Bryan, Jennifer Aprea, Disability Rights Tennessee, the Tennessee Disability Coalition, The Arc Tennessee, The Arc of the United States, Civil Rights Education and Enforcement Center, Disability Rights Education and Defense Fund, Autistic Self Advocacy Network, Epilepsy Foundation of Middle & West Tennessee, National Kidney Foundation, and National Multiple Sclerosis Society

Dear Mr. Severino:

We are individuals with disabilities and disability rights organizations representing and advocating for the rights of individuals with disabilities in Tennessee.¹ We include Disability Rights Tennessee, the designated Protection & Advocacy agency for Tennessee. We write with great urgency to alert you to Tennessee's guidelines for rationing scarce resources during a public health emergency. Those guidelines exclude people with disabilities from critical care, including ventilators, in violation of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), and Section 1557 of the Affordable Care Act (Section 1557).

The ADA, Section 504, and Section 1557 cover the state of Tennessee and all Tennessee hospitals, health care providers, health plans and insurers. As documents previously provided to you and your office make clear,² these federal laws prohibit disability discrimination in medical decision-making. The attached complaint filed last week by Disability Rights

¹ Please see our further descriptions at the end of this letter.

² March 20, 2020 letter of the Consortium of Citizens with Disabilities, at <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>; March 23, 2020 Disability Discrimination Complaint Filed Over Covid-19 Treatment Rationing Plan in Washington State, at <https://www.disabilityrightswa.org/2020/03/23/disability-discrimination-complaint-filed-over-covid-19-treatment-rationing-plan-in-washington-state/>, and attached hereto; Disability Rights Education and Defense Fund, Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability, at <https://dredf.org/the-illegality-of-medical-rationing-on-the-basis-of-disability/>.

Washington and others details these principles. Yet Tennessee’s 2016 “Guidelines for the Ethical Allocation of Scarce Resources”³ permit and advise that, in the context of a crisis like COVID-19, health care providers discriminate on the basis of disability in violation of federal law.

Specifically, Tennessee’s guidelines exclude people with “advanced neuromuscular disease” who require “assistance with activities of daily living or requiring chronic ventilatory support,” from accessing critical care, including ventilators. They further exclude people with metastatic cancer, some people with dementia, and some people with traumatic brain injury from necessary care. The thousands of people who have the listed conditions in the guidelines are not inherently less likely to respond to COVID-19 treatment or medically less capable of surviving and returning to living productive and valued lives. A diagnosis should not determine anyone’s right to individual medical judgment or leave people afraid to seek professional help because their care will be based on assumptions about a condition. As such, these guidelines violate the federal disability rights laws outlined above.

As a result of these guidelines, and the message that they send about the worth and dignity of people with disabilities, Tennesseans with significant disabilities are experiencing intense fear and anxiety. People with disabilities fear that, should they need critical care or ventilators during the COVID-19 crisis, they may be excluded and denied based on disability, and may even face preventable death.

Erin Brady Worsham is an artist and writer.⁴ In 1994, she was diagnosed with amyotrophic lateral sclerosis (ALS or Lou Gehrig’s Disease) and was given three years to live. Since that time, Erin has not only continued living but has flourished. She and her family have lived in East Nashville for 30 years and love it, and especially love the iconic Tomato Art Fest held in August. She has participated in the Tomato Art Show since 2012 and was delighted to have her piece “Revelation” win the 2019 Heirloom Award. Erin’s art has been seen in exhibits around the United States, as well as in Canada and Australia. She operates the computer and composes her pictures with a switch taped between her eyebrows. Each picture can take anywhere from 60 to 300 hours. Because Erin has ALS, is ventilator dependent, and is now also living with metastatic cancer, Tennessee’s medical rationing guidelines exclude her from receiving COVID-19 treatment. Erin adds, “I am a human being who happens to have a serious disability and I deserve treatment like anyone else. This policy discriminates against those of us who have already faced many challenges.”

Jean Marie Lawrence was born with Muscular Dystrophy. She is 33 years old and relies on a ventilator for 12 to 20 hours a day. She works 40 hours a week, volunteers, and lives independently. Because Jean Marie has Muscular Dystrophy and is ventilator dependent,

³ Tennessee Altered Standards of Care Workgroup, “Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee” (July 2016), at https://www.tn.gov/content/dam/tn/health/documents/2016_Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf.

⁴ Erin’s full bio. is attached.

Tennessee's medical rationing guidelines exclude her from receiving COVID-19 treatment. Jean Marie shares, "Tennessee is saying my life is worth less than that of someone without my disability. I fear not only for myself but also for the millions of other Tennesseans with disabilities whose lives you may see as untraditional but are nonetheless worth every bit as much as your own."

Erin and Jean Marie's stories are just two examples of Tennesseans with disabilities who are at risk of being excluded from medical treatment and who, as a result, risk facing preventable death. The stories of the other individual Complainants follow in the Further Description of Complainants at the end of this letter. In passing the ADA, our nation promised to include individuals with disabilities as equal members of our communities in all contexts, including this one. We need your leadership to protect the rights of Erin, Jean Marie, John and Pam Bryan, Jennifer Aprea and other Tennesseans with disabilities and their family members during this crisis.

We request that OCR immediately investigate and resolve this complaint of disability discrimination, and promptly detail what the state of Tennessee and Tennessee health care providers must do to comply with federal laws protecting the rights of all patients, including those with disabilities, during the COVID-19 pandemic. We need your guidance immediately, given that the pandemic is spreading at a rapid pace and the number of confirmed cases and deaths is climbing each day.

Please contact Lisa Primm or Sherry Wilds of Disability Rights Tennessee at 615.298.1080 ext. 118 or by email to lisap@disabilityrightstn.org and sherryw@disabilityrightstn.org with any questions or responses to this complaint.

Sincerely,

Lisa Primm
Sherry Wilds
Disability Rights Tennessee

Carol Westlake
Donna DeStefano
Tennessee Disability Coalition

Carrie Hobbs Guiden
The Arc Tennessee

Shira Wakschlag
The Arc of the United States

Martie Lafferty
Civil Rights Education and Enforcement
Center

Claudia Center
Disability Rights Education and Defense Fund

Sam Crane
Autistic Self Advocacy Network

Jennifer Mathis
The Bazelon Center for Mental Health Law

Eliza Herzen
Epilepsy Foundation of Middle & West
Tennessee

Michelle Dicken, East and Middle Tennessee
Mable Barringer, West Tennessee
National Kidney Foundation

Abby Emanuelson
National Multiple Sclerosis Society

Samuel Bagenstos

Cathy Costanzo
Alison Barkoff
Center for Public Representation

Further Descriptions of Complainants

Individual Complainants

Erin Brady Worsham Erin's story is included in the body of this letter. See also Erin's attached bio.

Jean Marie Lawrence Jean Marie's story is included in the body of this letter.

Jennifer Aprea Jennifer's son Ryan is 8 years old. He was born at 25 weeks and spent his first 7 months in the NICU. He had a hard time coming off oxygen and had pulmonary hypertension secondary to his chronic lung disease. He has grown out of his lung issues and came off oxygen at the age of 3. His remaining disabilities are: deafness, visual impairment, I/DD, and he was recently diagnosed with autism. Jennifer's biggest fear as a parent is that if Ryan were to contract COVID-19 he could be one of the patients who would require a ventilator based on his past history of lung issues. Jennifer fears that, because of his high needs and the fact that he's non-verbal and has multiple disabilities, Ryan would be excluded from life-saving measures. Ryan is an eight-year-old child with his entire life ahead of him, and just knowing as a mother that there is a policy in place that might require her to take Ryan home to watch him die has increased Jennifer's anxiety to a level that is inexplicable. Ryan already fought for 7 months in the NICU to come home and live his life with his family. Ryan should not be denied the proper medical treatment and chance to fight during this pandemic just because of his past medical history and disabilities.

John and Pam Bryan Twenty-five years ago after a car crash, 13-year-old John Bryan was not expected to survive. He sustained a severe traumatic brain injury (TBI) and spinal cord injury. He did survive and even though his mother Pam was told he would never wake up, he graduated from high school with a regular diploma four years later. Along with his TBI, John has had Type 2 diabetes for 27 years. He also has many additional medical concerns. Two years ago, doctors said there is nothing else they can do for John and did not expect him to make it for another six months...but they were wrong again. John and his family have enjoyed and continue to enjoy many good times together in the 25 plus years since the car crash. Life is good for John and his family. John wants to be resuscitated if that is ever needed. Pam says, "Why should a doctor who does not know John's past or present make the decision of whether he receives life-saving treatment based on his disability? The doctors have been wrong before, they could be wrong again. Who's to know the answer but God."

Toni Corbin Toni's son Wallace is 42 years old. He has paralysis and a severe traumatic brain injury. Wallace uses a Trilogy Ventilator when he sleeps. He was in the hospital about half a dozen times last year and the hospital put him on a ventilator on several occasions. Due to his disability and Tennessee's guidelines, Toni is concerned that Wallace will not get a ventilator if he is hospitalized with COVID-19.

Organizational Complainants

Disability Rights Tennessee is the designated Protection & Advocacy agency for residents of Tennessee who have physical, mental, or developmental disabilities pursuant to the federal protection and advocacy acts and state law.⁵ The Protection & Advocacy Systems were mandated by the federal government in each state, district, commonwealth, territory, and the Native American Nations in the four corners region to provide independent advocacy for people with disabilities who are subjected to abuse, neglect, and serious rights violations.

The Tennessee Disability Coalition is an alliance of organizations and individuals joined to promote the full and equal participation of people with disabilities in all aspects of life. We rely on grassroots support from individuals and families across the state. The work of self-advocates and small local groups is critical to the success of our combined goals. In addition to their contributions, we have a formal membership of 47 organizations. The Coalition and its member organizations represent Tennesseans of every age, economic background, political persuasion and disability. Each organization is committed to collaboration toward improving the lives of all Tennesseans who are touched by a disability.

The Arc Tennessee is a grassroots, non-profit, statewide advocacy organization for people with intellectual and developmental disabilities and their families. Founded in 1952, The Arc Tennessee is affiliated with The Arc United States and works collaboratively with local chapters across Tennessee.

The Arc of the United States is the nation's largest organization of and for people with intellectual and developmental disabilities (I/DD). The Arc promotes and protects the human and civil rights of people with I/DD and actively supports their full inclusion and participation in the community. Included in The Arc's chapter network of over 600 chapters nationwide is The Arc Tennessee as well as fifteen local chapters throughout the state. The Arc has a vital interest in ensuring that all individuals with I/DD receive the protections and supports to which they are entitled by law. The organization has long worked to ensure that people with I/DD are protected from discrimination in receiving medical care.

Civil Rights Education and Enforcement Center is a nonprofit membership organization whose goal is to ensure that everyone can fully and independently participate in our nation's civic life without discrimination based on disability or other protected status. Our scope is nationwide and we have offices in Colorado, California, and Tennessee. Through our Accessibility Project, CREEC works to ensure that people with disabilities have equal access and opportunities.

The Disability Rights Education and Defense Fund is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through

⁵ Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041 et seq.; the Protection and Advocacy for Individuals with Mental Illnesses Act, as amended, 42 U.S.C. § 10801, et seq.; the Protection and Advocacy for Individual Rights Act, 29 U.S.C. § 794e; and RCW 71A.10.080.

legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives. DREDF's work is based on the knowledge that people with disabilities of varying racial and ethnic backgrounds, ages, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports and the reasonable accommodations and modifications enshrined in U.S. law.

The Autistic Self Advocacy Network is a nonprofit organization run by and for autistic people. ASAN was created to serve as a national grassroots disability rights organization for the autistic community, advocating for systems change and ensuring that the voices of autistic people are heard in policy debates and the halls of power. Our staff work to advance civil rights, support self-advocacy in all its forms, and improve public perceptions of autism. ASAN's members and supporters include autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators, and friends.

National Kidney Foundation is a lifeline for all people affected by kidney disease. As pioneers of scientific research and innovation, NKF focuses on the whole patient through the lens of kidney health. Relentless in our work, we enhance lives through action, education and accelerating change.

National Multiple Sclerosis Society funds cutting-edge research, drives change through advocacy, and provides programs and services to help people affected by MS live their best lives. Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system. There is currently no cure for MS. Symptoms vary from person to person and range from numbness and tingling, to mobility challenges, blindness and paralysis. An estimated 1 million people live with MS in the United States. Most people are diagnosed between the ages of 20 and 50, and it affects women three times more than men.



ERIN BRADY WORSHAM...ARTIST ALWAYS!

Nashville artist and writer, **Erin Brady Worsham**, did not study art until she was 34.

A 1980 graduate of Western Kentucky University with majors in Theater and German, Worsham spent some years on the road as a professional actress. She married fellow actor Curry Worsham in 1987 and they settled in Nashville, TN. She enrolled in Watkins Art Institute in 1991 and found her calling. Having grown up in Louisville, KY, with a mother who was an artist, she was no stranger to art, but had never formally studied. At Watkins she received a classical education in theory, technique and history.

Life changed dramatically for Worsham and her husband on Sept. 7, 1994, when she received a diagnosis of amyotrophic lateral sclerosis (ALS or Lou Gehrig's Disease) and was given three years to live. She was just 36. All art stopped, but not all creating. Nine months after the diagnosis, Worsham gave birth to the couple's first and only child.

In the summer of 1999, Curry installed the software that would allow her communication device to interface with their computer and move the mouse. Worsham began to reclaim her art! She operates the computer and composes her pictures with a switch taped between her eyebrows. Each picture can take anywhere from 60 to 300 hours. Her first piece, "Big Wheels Keep on Turnin'," was completed in May of 2000.

Since that time her work has been seen in exhibits around the United States, as well as in Canada and Australia. Worsham's first one-woman show, "Artist Always," sponsored by Vanderbilt University Hospital and the Society for the Arts in Healthcare, began touring the country in 2003. In April of 2004, the show was on display in the Russell Rotunda in Washington, D.C.

Worsham's second one-woman show, "Artist's Proof," opened in March of 2007 at the Tennessee Arts Commission and received favorable reviews. Her third one-woman show, "Framed," opened at Studio East in East Nashville in November of 2010, in response to the incredible community support following the foreclosure and subsequent reinstatement of her family's home.

Worsham has participated in disability arts festivals and exhibits around the world, including kickstART! and kickstART2 in Vancouver, B.C., the High Beam Festival in South Australia, the VSA International Arts Festival in Washington, D.C., the Chicago Disability Arts and Culture Festival, the Survivor Art Foundation's "Breaking the Walls of Bias" Exhibit at the Hofstra Museum in New York and "The Artist's Voice" Exhibit at the Frist Center for the Visual Arts in Nashville, Tennessee.

Worsham was chosen to create the art for the 2015 poster and fine art giclee for the National Center for Farmworker Health in Texas. An artist is chosen annually and the posters and giclees are sold to raise money for scholarships. That same year, Worsham's piece, "I am the One," was selected to be the program and t-shirt design for the 2015 Tennessee Disability Megaconference. Subsequently, her piece, "Put Your Heads Together, People!," was chosen to be the program and t-shirt design for the 2017 Tennessee Disability Megaconference.

Worsham's work has garnered her several awards, including the 1999 MDA Personal Achievement Award, the 2001 Jo Andrews Award (Metropolitan Nashville Government), the 2003 Alumnae of the Year (Sacred Heart Academy, Louisville, KY), the 2004 Spirit of da Vinci Award (Engineering Society of Detroit/National Multiple Sclerosis Society, Michigan Chapter) and the 2005 Truth in Media Award (Tennessee Right to Life).

Using her communication device, Worsham has given talks on art and advocacy. She was a featured speaker at the 2006 National Right to Life Convention and the 2007 Megaconference, both in Nashville. Over the years, Worsham has given many talks about her art to the Partners in Policymaking classes, the most recent being to the Class of 2019. Partners in Policymaking is a state advocacy program for people with disabilities and their families.

Worsham and her family have lived in East Nashville for 30 years and love it, and especially love the iconic Tomato Art Fest held in August. She has participated in the Tomato Art Show since 2012 and was delighted to have her piece "Revelation" win the 2019 Heirloom Award.

Challenges are not over for Worsham and her family. In September of 2018, Stage 3 cancer was discovered in her colon and removed. In February of 2020, it was confirmed that cancer had returned and appears to have metastasized in her liver. With God's help, the fight goes on!



Disability Rights WASHINGTON

Washington's protection and advocacy system

March 23, 2020
Roger Severino
Director, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington DC 20201

RE: *Complaint of Disability Rights Washington, Self Advocates in Leadership, The Arc of the United States, and Ivanova Smith Against the Washington State Department of Health (WA DOH), the Northwest Healthcare Response Network (NHRN) and the University of Washington Medical Center (UWMC)*

Dear Mr. Severino:

We are submitting this complaint about illegal disability discrimination that is putting the lives of people with disabilities at imminent risk during the COVID-19 pandemic. As COVID-19 cases increase, the experience in other countries and predictions of U.S. health officials is that there will not be enough acute care services or equipment, such as ventilators, to meet the demand of patients with the virus who require intensive treatment. Health care professionals in the United States are already developing protocols for responding to COVID-19, including treatment rationing that will determine who will and will not have access to life-saving treatment. While we recognize the need to plan and be prepared for this potential reality during these extraordinary times, the guiding principles that are adopted must be consistent with federal civil rights law.

This complaint concerns the rationing scheme being put in place in Washington State, which discriminates against people with disabilities in violation of federal disability rights laws, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), and Section 1557 of the Affordable Care Act (ACA). Washington's rationing scheme places the lives of disabled people at serious risk. It is critical that the Office for Civil Rights (OCR) take immediate action to address this discrimination and assist covered entities in developing non-discriminatory approaches before there are lethal consequences from the application of these illegal policies.

The Washington State Department of Health (WA DOH) and the Northwest Healthcare Response Network (NHRN), a coalition of hospitals, are developing a plan to ration health care during the COVID-19 pandemic. "Washington state and hospital officials have been meeting to consider what once was almost unthinkable — how to decide who lives and dies if, as feared, the coronavirus pandemic overwhelms the state's health care system."¹ As described by the

¹ Mike Carter, "It will not be pretty: State preparing to make life-or-death decisions if coronavirus overwhelms health care system," *Seattle Times* (March 20, 2020), <https://www.seattletimes.com/seattle-news/it-will-not-be-pretty-state-preparing-to-make-life-or-death-decisions-if-coronavirus-overwhelms-health-care-system/>

NHRN, if the plan is implemented “it will not be pretty.”² It is reported that the plan “will assess factors such as age, health and likelihood of survival in determining who will get access to full care and who will merely be provided comfort care, with the expectation that they will die.”³ While discussions about the details of the plan may be evolving,⁴ it is clear that it will discriminatorily disadvantage people with disabilities. For example, [guidance](#) distributed by the WA DOH last week recommends that triage teams consider transferring hospital patients with “loss of reserves in energy, physical ability, cognition and general health” to outpatient or palliative care.⁵ Published descriptions of the goals and flow charts in the WA DOH and NHRN plan mirror the existing policy of the state-run University of Washington Medical Center (UWMC), which gives priority to treating people who are younger and healthier and leaves those who are older and sicker—people with disabilities—to die.⁶ Any plan that discriminates against people with disabilities in this way violates the legal rights of people with disabilities and is unlawful.

The disability advocacy organizations Disability Rights Washington (DRW), Self Advocates in Leadership (SAIL), and The Arc of the United States (The Arc), along with Ivanova Smith as an individual and self-advocate (together “the Complainants”), file this complaint on behalf of their constituents, Washingtonians with disabilities who will likely die if medical professionals are allowed to withhold health care services from them. These constituents include “Rose,”⁷ an individual with cystic fibrosis.

DRW is a private non-profit organization that serves as the designated Protection and Advocacy System for the State of Washington for residents of this state who have physical, mental, or developmental disabilities pursuant to the federal protection and advocacy acts and state law.⁸ The Protection and Advocacy Systems were mandated by the federal government in each state, district, commonwealth, territory, and the Native American Nations in the four corners region to provide independent advocacy for people with disabilities who are subjected to abuse, neglect, and serious rights violations.

SAIL is a statewide coalition in Washington State of people with developmental disabilities. SAIL strives to shape public policies that affect the lives of people with developmental disabilities. Its members are concerned about how the allocation policies reflected in this complaint could

² *Id.*

³ Karen Weise and Mike Baker, “‘Chilling’ Plans: Who Gets Care as Washington State Hospitals Fill Up?,” *New York Times* (March 20, 2020), <https://www.nytimes.com/2020/03/20/us/coronavirus-in-seattle-washington-state.html>

⁴ *Id.*

⁵ Sheri Fink, “The Hardest Questions Doctors May Face: Who Will Be Saved? Who Won’t?,” *New York Times* (March 21, 2020), <https://www.nytimes.com/2020/03/21/us/coronavirus-medical-rationing.html>

⁶ Material Resource Allocation Principles and Guidelines - COVID-19 Outbreak, University of Washington Medical Center, available at <https://covid19.uwmedicine.org/Screening%20and%20Testing%20Algorithms/Other%20Inpatient%20Clinical%20Guidance/Clinical%20Care%20in%20ICU/Material%20Resource%20Allocation.COVID19.docx>.

⁷ Due to fear of retaliation, the constituent’s name has been changed to protect her identity.

⁸ Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041 *et seq.*; the Protection and Advocacy for Individuals with Mental Illnesses Act, as amended, 42 U.S.C. § 10801, *et seq.*; the Protection and Advocacy for Individual Rights Act, 29 U.S.C. § 794e; and RCW 71A.10.080.

deny care to their members and constituents. Historically, people with intellectual and developmental disabilities (I/DD) have been subject to a long history of discrimination and dehumanization in the health care system. Many people with disabilities have had their medical rights taken away and been denied needed care, including life-sustaining treatment.

The Arc is the nation's largest organization of and for people with I/DD. The Arc promotes and protects the human and civil rights of people with I/DD and actively supports their full inclusion and participation in the community. Included in The Arc's chapter network of over 600 chapters are ten chapters throughout the State of Washington, including The Arc of Washington State. The Arc has a vital interest in ensuring that all individuals with I/DD receive the protections and supports to which they are entitled by law. The organization has long worked to ensure that people with I/DD are protected from discrimination in receiving medical care.

Ivanova Smith is an individual with a developmental disability affected by the allocation guidelines now in place in Washington State. She is concerned about how the guidelines will affect her and her peers. As a well-known and effective disability rights advocate in the state legislature, administration, and community, Mrs. Smith—along with the peers she advocates with and on behalf of—will be at greater risk of discrimination under the WA DOH and UWMC guidelines in the event she were to fall ill with COVID-19 or another condition requiring the use of scarce medical resources.

Recent policies put in place by UWMC and WA DOH would place many people with disabilities, including Mrs. Smith, at risk of great harm and even death. Many among Complainants' members have weakened immune systems that may mean they will require additional time and resources, including scarce medical resources, in recovering from COVID-19 and other medical issues. In addition, Complainants' membership and constituents may be erroneously seen as having lower quality of life, justifying denying, withdrawing, or giving lower priority for treatment with scarce medical resources. Complainants believe that their members and constituents and the disability community more broadly should not be denied care based on their disability and their needs for reasonable accommodations and modifications.

The Complainants request that OCR immediately investigate and quickly issue findings and guidance specifying how physicians and hospitals are to refrain from violating the ADA, Section 504, and Section 1557 of the ACA in making treatment decisions.

As noted in a recent letter to your office from the Consortium for Citizens with Disabilities:⁹

Your office has long stood on guard against medical rationing schemes that discriminate against and otherwise devalue the lives of people with disabilities. In 1992, then-Secretary Louis Sullivan, relying on advice from your office and the Department of Justice, rejected Oregon's proposed health plan precisely because its rationing provisions discriminated in violation of the Americans with Disabilities Act. In support of that decision, Secretary Sullivan explained that a

⁹ Consortium for Citizens with Disabilities, Letter to Secretary Azar and Director Severino, March 20, 2020, <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>.

covered entity may consider “a wide range of factors” that are “consistent with the ADA.”¹⁰ Covered entities, he explained, “may consider, consistent with the ADA, any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities.”¹¹ But they may not discriminate against qualified individuals with disabilities. Nor may they employ factors that rest “in substantial part on the premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability.”¹²

The existence of widespread discrimination against people with disabilities in the medical community when making treatment decisions is well established.¹³ More generally, as HHS’s legal analysis of the Oregon health plan stated, “[s]cholars who have examined quality of life surveys have concluded that as compared to persons who have the disabilities in question, persons without disabilities systematically undervalue the quality of life of those with disabilities.”¹⁴ As Justice Neil Gorsuch has written in explaining his opposition to physician-assisted suicide, “[a]ll human beings are intrinsically valuable...any line we might draw between human beings for purposes of determining who must live and who may die ultimately seems to devolve into an arbitrary exercise of picking out which particular instrumental capacities one especially likes.”¹⁵ Justice Gorsuch notes the history of societal devaluation of people with disabilities embodied by the eugenics movement, and the inherent risk for abuse the medical system poses for people with disabilities, particularly with regards to end-of-life treatment.¹⁶

OCR has a very brief moment to intercede. If OCR fails to act swiftly to clearly and firmly articulate the violation of civil rights implicated by the rationing plan about to be unveiled in Washington, there will be no way to undo the lethal outcome of the discriminatory plans that have been formulated without OCR’s guidance. We implore you to enforce the obligations of the health care professionals in Washington to develop non-discriminatory approaches to the delivery of care before it is too late.

Federal Law Prohibits Discrimination Against People with Disabilities in the Provision of Medical Treatment

Federal law prohibits public and private actors from discriminating against people with disabilities.¹⁷ Based on Washington’s existing protocols and recent news reports, it appears that

¹⁰ Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration (Attachment to Letter from Louis W. Sullivan to Governor Barbara Roberts (Aug. 3, 1992)), reprinted in 9 *Issues in Law & Medicine* 397 (1994) (hereafter “HHS Analysis of Oregon Health Plan”).

¹¹ *Id.*

¹² *Id.*

¹³ See, e.g., David Carlson, Cindy Smith, Nachama Wilker, *Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights*, National Disability Rights Network and Disability Rights Washington p.40 (2012), http://ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf. See generally pp. 8-11 below (describing history of disability discrimination in medical care).

¹⁴ HHS Analysis of Oregon Health Plan, *supra* note 10.

¹⁵ Neil Gorsuch, *The Future of Assisted Suicide and Euthanasia*, New Forum Books (2006).

¹⁶ *Id.*

¹⁷ See e.g. Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213 (2000)

the state is poised to make decisions on a basis that will deny needed medical treatment to countless individuals based on their underlying disabilities—without an individualized inquiry and determination about the efficacy of treatment and the individual’s ability to survive the virus. Those discriminatory decisions will lead disabled people to die simply because of their disabilities. That is a violation of disability discrimination laws.

Legal Background

In 1990, Congress acted to combat the widespread discrimination against people with disabilities. It specifically found that historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.¹⁸ The purpose of the ADA is to provide “a clear and comprehensive national mandate for the elimination of discrimination”¹⁹ and “clear, strong, consistent, enforceable standards addressing discrimination.”²⁰ Regardless of the type or severity of a person’s disability, the ADA rests on the premise that discrimination inherently causes harm to both the person who experiences the discriminatory conduct and society as a whole. The current form of discrimination—rationing treatment on the basis of disability—will leave large numbers of people with disabilities to die simply because of their disabilities.

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.

WA DOH’s rationing plan violates Title II of the ADA and its implementing regulations by authorizing actions that:

- A. Deny a qualified individual with a disability the benefits of the services, programs, or activities of a public entity because of the individual’s disability.²¹
- B. “Aid or perpetuate discrimination against a qualified individual with a disability by providing significant assistance to an agency, organization, or person that discriminates on the basis of disability in providing any aid, benefit, or service to beneficiaries of the public entity’s program.”²²
- C. “[L]imit a qualified individual with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving the aid, benefit, or service.”²³
- D. “[D]eny a qualified individual with a disability the opportunity to participate in services, programs, or activities that are not separate or different, despite the existence of permissibly separate or different programs or activities.”²⁴

¹⁸ *Id.* at § 12101(8),(9).

¹⁹ *Id.* at § 12101(b)(1).

²⁰ *Id.* at § 12101(b)(2).

²¹ *Id.* at § 12132.

²² 28 C.F.R. § 35.130(b)(1)(v).

²³ 28 C.F.R. § 35.130(b)(1)(vii).

²⁴ 28 C.F.R. § 35.130(b)(2).

- E. “Directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities; or (iii) That perpetuate the discrimination of another public entity if both public entities are subject to common administrative control or are agencies of the same State.”²⁵
- F. Fail to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.”²⁶
- G. “Impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.”²⁷

Similarly, NHRN and its members violate Title III of the ADA and its implementing regulations by:

- A. Discriminating “on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation.”²⁸
- B. Subjecting “an individual or class of individuals on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of a place of public accommodation.”²⁹
- C. Using “standards or criteria or methods of administration that have the effect of discriminating on the basis of disability, or that perpetuate the discrimination of others who are subject to common administrative control.”³⁰
- D. Imposing or applying “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations,” even though such criteria are not necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered.³¹

²⁵ 28 C.F.R. § 35.130(b)(3).

²⁶ 28 C.F.R. § 35.130(b)(7).

²⁷ 28 C.F.R. § 35.130(b)(8).

²⁸ 28 C.F.R. § 36.201(a).

²⁹ 28 C.F.R. § 36.202(a).

³⁰ 28 C.F.R. § 36.204.

³¹ 28 C.F.R. § 36.301(a).

- E. Failing to “make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities.”³²

Section 504 also prohibits discrimination against people with disabilities by entities that receive federal financial assistance. DOH and NHRN’s members are recipients of federal financial assistance, and have engaged in unlawful discrimination under Section 504, including:

- A. Excluding from participation in, denying the benefits of, or otherwise subjecting to discrimination on the basis of disability.³³
- B. Denying qualified persons with a disability the opportunity to participate in or benefit from the aid, benefit, or service.³⁴
- C. Affording qualified persons with a disability an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others.³⁵
- D. Limiting individuals with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.³⁶
- E. Using criteria or methods of administration that have the effect of subjecting qualified persons to discrimination on the basis of disability, or that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of program or activity with respect to persons with disabilities.³⁷
- F. Failing to make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities.³⁸

Section 1557 of the ACA prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities. WA DOH and NHRN violate the ACA through their actions that:

- A. “[D]en[y] the benefits of, or otherwise be subjected [a person with a disability] to discrimination under any health program or activity to which this part applies”³⁹
- B. Fail to “make reasonable modifications to policies, practices, or procedures when such modifications are necessary to avoid discrimination on the basis of disability.”⁴⁰

³² 28 C.F.R. § 36.302(a).

³³ 29 U.S.C. § 794(a); 45 C.F.R. §§ 84.4(a) and 84.52(a)(1); 28 C.F.R. § 41.51(a).

³⁴ 45 C.F.R. § 84.4(b)(1)(i); 28 C.F.R. § 41.51(b)(1)(i).

³⁵ 45 C.F.R. §§ 84.4(b)(1)(ii) and 84.52(a)(2); 28 C.F.R. § 41.51(b)(1)(ii).

³⁶ 45 C.F.R. §§ 84.4(b)(1)(vii) and 84.52(a)(4); 28 C.F.R. § 41.51(b)(1)(vii).

³⁷ 45 C.F.R. §§ 84.4(b)(4) and 84.52(a)(4); 28 C.F.R. § 41.51(b)(3).

³⁸ *Southeastern Community College v. Davis*, 442 U.S. 397 (1979); *Henrietta D. v. Bloomberg*, 331 F.3d 261, 273–76 (2d Cir. 2003).

³⁹ 45 C.F.R. § 92.101.

⁴⁰ 45 C.F.R. § 92.205.

Application of Legal Principles

One of the most important principles of disability discrimination law is that it prohibits covered entities from acting based on myths, stereotypes, and unfounded assumptions about people with disabilities.⁴¹ Covered entities must instead make individualized determinations, based on current objective medical evidence.⁴²

Applying this principle and the regulatory requirements above to the allocation of scarce medical treatment during a crisis, the ADA, Section 504 and Section 1557 require the following:

- Decisions about how treatment should be allocated must be made based on individualized determinations, using current objective medical evidence, and not based on generalized assumptions about a person's disability. The mere fact that a person has diabetes, depression, an intellectual disability, or a mobility impairment, for example, cannot be a basis for denying care or making that person a lower priority to receive treatment.
- Treatment allocation decisions cannot be made based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living.
- Treatment allocation decisions cannot be made based on the perception that a person with a disability has a lower prospect of survival. While the possibility of a person's survival may receive some consideration in allocation decisions, that consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities. In addition, it must be based on a clear indication from the person's individual circumstances, interpreted according to the best available medical evidence in a manner free from bias, that the person will die in the very short term whether treatment is provided or not.
- Treatment allocation decisions cannot be made based on the perception that a person's disability will require the use of greater treatment resources. 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 or other modifications or additional services needed due to a disability.

WA DOH and NHRN violate the ADA, Section 504, and Section 1557 by authorizing the denial of treatment to individuals with disabilities and/or lower priority for individuals with disabilities to receive treatment based on misguided assumptions about the quality of life, the value of life, the prospects for survival, and the resource needs of people with disabilities, without the type of individualized determinations required by the law.

People with Disabilities Have Long Experienced Discrimination in the Provision of Medical Treatment

Studies have repeatedly documented a persistent bias by medical providers against people with

⁴¹ *School Bd. of Nassau County v. Arline*, 480 U.S. 273 (1987).

⁴² *Bragdon v. Abbott*, 524 U.S. 624 (1998).

disabilities -- and, notably, a persistent failure of medical providers to fully appreciate the value and quality of life with a disability. These problems are reinforced by the dramatic underrepresentation of disabled people in the health professions.

Discrimination is not always driven by malice. In the case of medical discrimination, often the discriminating provider claims they were simply trying to do what was in the patient's best interest and do not view their actions as discriminatory. Nonetheless, many people with disabilities who seek treatment are denied treatment because medical professionals improperly decide that would be best based on implicit biases about the quality of life and inherent worth of people with disabilities.⁴³

To start, medical decisions are some of the more difficult and personal decisions anyone makes. These decisions are affected by innumerable factors including sex, race, religion, and financial resources.⁴⁴ Disability status is also an important factor affecting decisions about life sustaining health care.⁴⁵

It can be hard for people without disabilities to understand or fully appreciate the scope and significance of the impact that disability status has on end of life treatment decisions. People with disabilities and the rest of the general public have differing views of what it is like to have a disability. Disability and bioethics scholar William Peace wrote about the night in 2010 when he was approached by a doctor who offered him a way to die.⁴⁶ He was fighting an infection and faced a long, expensive and painful path to recovery that would probably include months in a nursing home and the possibility he may never sit up in his wheel chair again.⁴⁷ The doctor he had never met before laid out the worst case scenario and then offered a path that would end Peace's pain, and life, much more quickly.⁴⁸ Peace wrote that "Many people – the physician I met that fateful night included – assume disability is a fate worse than death."⁴⁹ He drives home how disconcerting and insulting this was in that it came from "A highly educated person who should be free of bias and bigotry [who] deems your very existence, your life, unworthy of living."⁵⁰ Mr. Peace points out his situation is not unique and it is widely understood by people with disabilities that they have very different experiences in hospitals and doctors' offices than people who do not have disabilities.⁵¹

The pervasiveness of negative views of disability among physicians cannot be understated.⁵²

⁴³ *Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights*, *supra*, note 13.

⁴⁴ See e.g., Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S., *Prevalence of disabilities and health care access by disability status and type among adults—United States*, 2016. MMWR Morb Mortal Wkly Rep. 2018;67(32):882–7.

⁴⁵ *Id.*

⁴⁶ William J. Peace, *Comfort Care as Denial of Personhood*, 42 Hasting Center Report 14 (2012).

⁴⁷ *Id.*

⁴⁸ *Id.* at 15.

⁴⁹ *Id.*

⁵⁰ *Id.*

⁵¹ *Id.* He points out that while people with disabilities who want to live must fight to get treatment, those with disabilities who forgo treatment and die are lionized as role models of heroism.

⁵² As an example, research has been done on the way in which pediatricians inform parents their children have down syndrome. Almost every mother in the study reported physicians referring to their children in derogatory and stigmatizing ways with labels and generalizations based upon diagnosis that have been rejected by people

One physician responding anonymously to a research study candidly admitted that:

In general, what I was taught in medical school and in my training is that disability – no matter what its form – is a bad thing and should be avoided at all costs. Lectures or seminars on [Down Syndrome] or other genetic syndromes are geared toward the description of the abnormalities...that children with congenital diseases may find their lives rich and valuable was hardly recognized, much less stressed.⁵³

Similarly, when people with disabilities were asked in focus group discussions about medical discrimination, one person pointed out that “[d]octors are trained to be academic. They are trained to think about what the disability is, not what the person can do. Very few doctors have positive examples when they explain diagnoses to new parents. Many of them are not even aware of the lives people with disabilities – even severe disabilities – are living.”⁵⁴ Another participant suggested that all doctors while in medical school should take a class on disabilities taught by a person with a disability. “Doctors need to come and sit with people with disabilities...They (doctors) think they know about us... but it is like they are window shopping at our lives.”⁵⁵

It is not hard to see how negative views of disability persist in the medical community.⁵⁶ Last fall, the National Council on Disability released a series of reports about numerous problems with the way bioethics and the medical profession at large relate to people with disabilities.⁵⁷ A recent medical study similarly showed open hostility to people with disabilities by a large segment of the medical community who refuse even to treat patients with disabilities.⁵⁸ A quarter of doctors in the study refused to schedule an appointment with potential patients who used wheelchairs.⁵⁹ Another recent survey confirmed that physicians “demonstrated

with disabilities and their families and advocates for quite some time. As recent as 1998, a mother who gave birth to a child who had Down Syndrome was informed of the condition by being told that her child was a “mongoloid.” Another mother who learned of her child’s diagnosis of Down Syndrome after she gave birth in 1992 was told by her doctor to get amniocentesis the next time she was pregnant so that she could “choose to terminate.” Brian Skotko, *Mothers of Children with Down Syndrome Reflect on Their Postnatal Support*, *Pediatrics* 64-77 at 71 (2005).

⁵³ *Mothers of Children with Down Syndrome Reflect on Their Postnatal Support*, at 65, *supra* note 52.

⁵⁴ *Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights*, *supra* note 13.

⁵⁵ *Id.*

⁵⁶ This medical bias against disability is not isolated to the United States and its medical institutions, the same study was conducted simultaneously in Spain with similar results were found. Brian Skotko, *Mothers of Children with Down Syndrome Reflect on Their Postnatal Support: An International Call for Change*, *Italian Journal of Pediatrics* 237-245 (2005).

⁵⁷ National Council on Disability, “Bioethics and Disability Report Series,” (2019)

<https://ncd.gov/publications/2019/bioethics-report-series>

⁵⁸ Pauline W. Chen, “Disability and Discrimination at the Doctor’s Office,” *The New York Times* (May 23, 2013), <https://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/>, citing Lagu T, Hannon NS, Rothberg MB, et al. *Access to Subspecialty Care for Patients With Mobility Impairment: A Survey*. *Ann Intern Med*. 2013;158:441–446. doi: <https://doi.org/10.7326/0003-4819-158-6-201303190-00003>

⁵⁹ *Id.*

superficial or incorrect understanding” of the ADA and other anti-discrimination laws.⁶⁰

Some in the bioethics community even believe that the concepts of dignity and rights do not apply to people with certain disabilities.⁶¹ As one bioethicist wrote of a young girl with intellectual and physical disabilities subjected to an involuntary surgery to prevent her growth by removing her uterus and mammary glands and administering high doses of hormones, the girl “is not deprived of anything that she values because she does not have the capacity to value her own existence, let alone to miss anything taken from her.”⁶² Another well regarded bioethicist goes one step further in talking about the same young girl: “[w]e are always ready to find dignity in human beings, including those whose mental age will never exceed that of an infant, but we don’t attribute dignity to dogs or cats, though they clearly operate at a more advanced mental level than human infants.”⁶³ He concludes that children with significant intellectual disabilities have no intrinsic value and whatever value they may have is merely a function of their family’s positive regard.⁶⁴

This bias against people with disabilities is not benign. Its impact can be seen in the way physicians provide treatment. Research has shown that disabled patients “experience health care disparities, such as lower rates of screening and more difficulty accessing services, compared to people without disabilities.”⁶⁵

Thus, not only do negative views of disability contribute to medical professionals deprioritizing delivery of treatment, but individuals with disabilities have frequently experienced more difficulty getting treatment in the past due to discrimination, which may now compound the factors used to deny them treatment for COVID-19 during this pandemic.

Discriminatory Rationing Plans Are Being Put in Place in Washington State

OCR has already received letters within the last week from the National Council on Disability,⁶⁶ the independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities, and the Consortium for Citizens with Disabilities,⁶⁷ the nation’s largest coalition of

⁶⁰ Nicole D. Agaronnik, Elizabeth Pendo, Eric G. Campbell, Julie Ressalam, and Lisa I. Iezzoni, *Knowledge Of Practicing Physicians About Their Legal Obligations When Caring For Patients With Disability*, HEALTH AFFAIRS VOL. 38, NO. 4: PHYSICIANS, MEDICARE & MORE (April 2019), <https://doi.org/10.1377/hlthaff.2018.05060>.

⁶¹ Merle Spriggs, *Ashley’s Interests Were Not Violated Because She Does Not Have Necessary Interests*, The American Journal of Bioethics, 52-54 (2010).

⁶² *Id.*

⁶³ Peter Singer, “A Convenient Truth,” *New York Times* (January 26, 2007), <https://www.nytimes.com/2007/01/26/opinion/26singer.html>.

⁶⁴ *Id.*, stating Ashley “is precious not so much for what she is, but because her parents and siblings love her and care about her.” Singer argues that infants are not persons, and as such killing them is not as morally bad as killing older humans. This is not an isolated theory in bioethics, Alberto Giubilini and Francesca Minerva argue in favor of “after birth abortions” being an option to parents when it is discovered a child is born with a disability. Alberto Giubilini, Francesca Minerva, *After – Birth Abortion: Why Should the Baby Live?*, J. MED. ETHICS (2012).

⁶⁵ Iezzoni LI. Eliminating health and health care disparities among the growing population of people with disabilities. *Health Aff. (Millwood)*. 2011;30(10):1947–54.

⁶⁶ National Council on Disability, Letter to Roger Severino (March 18, 2020), <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>

⁶⁷ Letter to Secretary Azar and Director Severino, *supra* note 9.

disability organizations, asking OCR to issue guidance to health care providers about their obligations to not discriminate against people with disabilities within the context of delivering COVID-19 related care. These longstanding, well-respected national organizations correctly recognize that rationing is coming and if medical professionals are left to their own devices, people with disabilities will bear the brunt of the fatalities in rationing plans. In the days since these letters came out, articles in the *New York Times*⁶⁸ and *Seattle Times*⁶⁹ have confirmed that the concerns addressed in those letters are already ripe as the state of Washington and health care providers across Washington have been in talks about rationing health care and the release of their plan is imminent. What has already been made clear is that the plan will leave people with disabilities to die, by virtue of simply having a disability, in order to preserve the system's capacity to treat people without disabilities.

WA DOH and NHRN are developing their plan behind closed doors. That is troubling in any circumstance dealing with decisions of life and death. But the lack of transparency is particularly important given the history of discrimination against people with disabilities in medical treatment.

What we do know is that the description of the future plan and the flow charts of the previously circulated plan are consistent with the existing plan developed for the state-run UWMC's policy on rationing during the COVID-19 pandemic. That policy specifically states that resources will be allocated pursuant to the following principles:

The standard construct for medical resource allocation in time of scarcity is based upon a utilitarian framework, often stated as making decisions that provide the greatest good for the greatest number. It is worth noting that this stance differs from the standard approach of clinicians, who see their ethical obligation as advocating for and prioritizing the care of a particular patient.

Greatest good, in a protracted clinical situation such as the COVID-19 outbreak, is generally considered maximizing survival of patients with COVID-19 within the institution *and the region*. Overall survival may be further qualified as healthy, long-term survival, recognizing that this represents weighting the survival of young otherwise healthy patients more heavily than that of older, chronically debilitated patients. Such weighting has general support in medicine and society-at-large.⁷⁰

This plan, which rations care on the basis of disability, is a clear violation of federal disability rights laws.

⁶⁸ "'Chilling' Plans: Who Gets Care as Washington State Hospitals Fill Up?," *supra* note 3; "The Hardest Questions Doctors May Face: Who Will Be Saved? Who Won't?," *supra* note 5.

⁶⁹ "'It will not be pretty': State preparing to make life-or-death decisions if coronavirus overwhelms health care system," *supra* note 1.

⁷⁰ Emphasis in the original, Material Resource Allocation Principles and Guidelines - COVID-19 Outbreak, University of Washington Medical Center, available at <https://covid-19.uwmedicine.org/Screening%20and%20Testing%20Algorithms/Other%20Inpatient%20Clinical%20Guidance/Clinical%20Care%20in%20ICU/Material%20Resource%20Allocation.COVID19.docx>.

The policy explicitly states that doctors will be instructed to *not* do what is best for their individual patients and instead deny them treatment if it would mean a younger, healthier person in the region could get treatment. Thus, if you have one ventilator, and two people who need it, the ventilator should go to the healthier person who is more likely to recover, although that patient may arguably need it less.

Moreover, the WA DOH and NHRN plan distributed last week states that “baseline functional status (consider loss of reserves in energy, physical ability, cognition and general health)” will be used as a factor in determining whether someone will get access to lifesaving treatment. This is a highly subjective open-ended exclusionary factor that invites physicians to make allocation decisions based on unchecked bias about quality of life of patients with disabilities that does not reflect the actual value those patients place on their lives. Physicians are afforded the sole, unfettered discretion to predict future prognosis as underlying health conditions interact with COVID-19 and the resources available to provide treatment. No guidance is given to how much weight should be given to one factor over another. This calculation is highly speculative and subject to bias and is compounded by requiring additional speculation about how long the critical care resource will be needed and prognosis with consideration to both current epidemiology and underlying illness.⁷¹ Extending this degree of discretion to medical professionals is incredibly dangerous given the bias many physicians hold.⁷² Unbridled speculation empowers physicians to apply their explicit and implicit biases to individuals with disabilities.

As an example of how DRW’s constituents are affected, Rose⁷³ is a current UWMC patient who fears for her life if this plan is in place if she gets sick from this pandemic. Rose is an established patient of the Cystic Fibrosis clinic at the UWMC. She is deeply concerned that UWMC’s resource allocation guidelines for COVID-19 and the WA DOH and NHRN plan circulated last week threaten her ability to access lifesaving care if she was to develop severe COVID-19 complications requiring mechanical ventilation.

Cystic fibrosis is typically perceived as a severe condition. If a clinician knows only that an adult patient has a diagnosis of cystic fibrosis, they are likely to make certain assumptions in the absence of a more detailed medical history: for example, severe pulmonary impairment, frequent hospitalizations and courses of IV antibiotics, and a reasonable expectation of death by age 30. At 28-year-old, Rose may at first glance look to be at the end of her expected life to a COVID-19 triage administrator responding to voluminous requests from providers across the region. Rose worries that the hospital will see her diagnosis and determine she poses an unreasonably high risk of not recovering and that even if she can recover, she is likely near the end of her expected life. Accordingly, if Rose needs lifesaving treatment, she is likely to be denied that treatment under Washington’s plan. However, a closer look would show that the

⁷¹ WA DOH and NHRN Scarce Medical Resource and Crisis Standards of Care, p.35 (March 16, 2020) https://nwhrn.org/wp-content/uploads/2020/03/Scarce_Resource_Management_and_Crisis_Standards_of_Care_Overview_and_Materials-2020-3-16.pdf.

⁷² *Id.* at 34.

⁷³ Due to fear of retaliation, the constituent’s name has been changed to protect her identity.

test of her breathing capacity shows she is above the 70th percentile when compared to the population at large, **not** people with cystic fibrosis, and she has never been hospitalized or received IV antibiotics.

The UWMC's "Material Resource Allocation Principles and Guidelines" emphasize maximizing survival. They further qualify "overall survival" as "healthy, long-term survival, recognizing that this represents weighting the survival of young otherwise healthy patients more heavily than that of older, chronically debilitated patients." Based on the assumptions about people with cystic fibrosis referenced above, Rose reasonably expects to be at risk of discrimination in any system that does not prohibit withholding treatment on the basis of underlying diagnosis. She has no confidence that any decision UWMC makes about whether she get lifesaving treatment during the COVID-19 pandemic will be based on her individual circumstance or sound medical evidence. She cannot be expected to simply trust that hospital officials in a triage situation will review and evaluate her past tests and medical history in sufficient detail to get beyond the existence of her cystic fibrosis diagnosis. Moreover, the policy offers no process by which she will be given notice of the decision and an opportunity to see what records and data the hospital has reviewed and the weight it was afforded. Nor does it offer a process by which she could challenge the determination to point out errors.

Rose's case shows how this plan will have a heavy impact on people with disabilities. While medical knowledge of COVID-19 is constantly evolving, it is known that having an underlying medical condition heightens the effect of the virus. The conditions frequently mentioned include compromised immune, respiratory, cardiovascular and endocrine systems. All of these are common symptoms of many different physical disabilities and when significant enough form the basis of the disability on their own. Therefore, people with existing disabilities are likely to be the ones who die from this pandemic.

Similarly, Ivanova Smith, the Chair of Complainant SAIL, is also impacted by the allocation guidelines now in place in Washington State and is concerned by how this might impact her peers. A person with an intellectual disability, Mrs. Smith is a parent of a young child, a homeowner and an experienced and effective disability rights advocate. But in the event that she was to fall ill with COVID-19 or another condition requiring the use of scarce medical resources, the Department of Health and UWMC guidelines both place Mrs. Smith and her peers at greater risk of discrimination. As a person with an intellectual disability, she would be at a disadvantage in accessing care due to the Department of Health's use of baseline functional status (including cognition) at multiple steps in their triage protocol, including in the allocation of critical care resources and their potential re-allocation (i.e, the withdrawal of life-sustaining treatment).

Mrs. Smith has a well-founded fear that such a policy will result in her being inappropriately denied medically indicated care by reason of her disability. "I know already intellectually disabled people get denied care because of being seen as lacking value," she said, adding that "I deserve the same rights as anyone else. These policies discriminate against me and put my life at risk."

Today the health care community in Washington is moving forward with a plan to carry out a policy that would effectively result in death sentences for people with disabilities like Rose and

Mrs. Smith, without individualized determinations or consideration of federal law requirements. They are choosing to place the great number of people who need COVID-19 treatment with either pre-existing or newly acquired significantly limiting health conditions to the side without offering treatment other than palliative care. Instead, they would focus on the people who do not have underlying health conditions. Doctors are actively choosing to usher the latter group to the front of the line to help them heal while the others wait to die.

Conclusion

Complainants request OCR immediately investigate and resolve this complaint of disability discrimination, and detail what Washington health care providers must do to comply with federal laws protecting the rights of all patients, including those with disabilities, during the COVID-19 pandemic. Guidance is needed within hours or days, not weeks or months given that Washington is at the epicenter of the U.S. epidemic—the pandemic is spreading at a rapid pace, and the number of confirmed cases and deaths is climbing each day.

Please contact David Carlson, Director of Advocacy of Disability Rights Washington, at 206-324-1521 or davidc@dr-wa.org with any questions or responses to this complaint.

Respectfully,

David Carlson
Disability Rights Washington
901 North Monroe Street, Suite 340
Spokane, WA 99201
davidc@dr-wa.org
206-324-1521

Shira Wakschlag
The Arc of the United States
1825 K St. NW, Suite 1200
Washington, D.C. 20006
wakschlag@thearc.org
202-534-3708

Jennifer Mathis
Bazelon Center for Mental Health Law
1090 Vermont Avenue, NW, Suite 220
Washington, DC 20005
jenniferm@bazelon.org
202-467-5730

Cathy Costanzo
Alison Barkoff
Center for Public Representation
22 Green Street
Northampton, MA 01060
ccostanzo@cpr-ma.org
abarkoff@cpr-us.org
413-586-6024

Samantha Crane
Autistic Self Advocacy Network
PO Box 66122
Washington, DC 20035
scrane@autisticadvocacy.org
202-509-0135

Samuel Bagenstos
625 South State Street
Ann Arbor, Michigan 48109
sbagen@gmail.com
734-647-7584