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April 6, 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 Law Center and Jodi Hansen on behalf of Jacob Hansen.

Amanda Longwell

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Dear Mr. Severino:

We write to you on behalf of the approximately 18 % of Utahns who have disabilities and are in danger of being given a lower priority for life-saving care than their non-disabled peers due to the rationing scheme currently being implemented in Utah. We realize that as a result of the COVID-19 pandemic, Utah may face shortages of critical equipment and need to create protocols that describe the way in which care is to be provided when resources are insufficient to treat all who may require assistance. However, any protocol cannot discriminate against individuals with disabilities. Unfortunately, Utah's Crisis Standards of Care Guidelines ("The Guidelines"), and specifically the Patient Prioritization Tool, Adult Triage Guidelines and Pediatric Triage Guidelines explicitly and implicitly deprioritize people with disabilities for care.¹ Such a scheme violates multiple civil 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). We therefore request the Office for Civil Rights (OCR) take immediate action to address this discrimination and direct all covered entities to immediately develop a non-discriminatory approach before it is too late.

The Disability Law Center ("DLC") is Utah's Protection and Advocacy—part of a nationwide network of agencies that work to protect the legal rights of disabilities. The DLC is empowered through federal statutes to ensure the legal rights of Utahns with disabilities are protected and specifically to monitor and investigate instances where people with disabilities are abused, neglected or subjected to other severe violations of their rights.² It is difficult to imagine any more serious concern within the DLC's purview than a policy which explicitly withholds life-saving treatment from people with

¹https://coronavirus.utah.gov/wp-content/uploads/Final_Utah_Crisis_Standards_of_Care_011719-1.pdf

² 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

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disabilities. In addition to the DLC, we bring this complaint on behalf of Jacob Hansen and his mother and guardian, Jodi. Jacob is 20 years old. He has cerebral palsy and cystic fibrosis. Jacob is served by Utah's Division of Services of People with Disabilities because he requires certain assistance with activities of daily living. He uses a wheelchair to assist with his mobility. Jacob has advocated for other people with disabilities in front of the Utah State Legislature and is committed to ensuring people with disabilities are given equal access to the benefits of our society. Through no fault of his own, Jacob, and countless others like him, will be subject to the State's unlawful rationing policies.

The Guidelines explicitly target individuals with disabilities in their "exclusion criteria" which include "known severe dementia" that requires "assistance with activities of daily living," as well as advanced neuromuscular disease such as ALS or end-stage MS that "require assistance with activities of daily living."³ Additionally, individuals with brain injuries and cystic fibrosis, along with many other categories of disability may also be excluded from care.⁴ The Guidelines' focus on assistance with activities of daily living is particularly concerning given the potentially wide array of impact. For example, an individual with multiple sclerosis who requires assistance walking, or a patient with dementia who required help preparing meals would be harmed by the policy regardless of whether the need for assistance with those activities affected the patient's ability to respond to treatment for COVID-19. Similarly, The Guidelines deprioritize children with underlying conditions who have functional limitations. Explicit in the exclusion criteria are children with "progressive neuromuscular disorder, e.g. muscular dystrophy and myopathy, with inability to sit unaided or ambulate when such abilities would be developmentally appropriate based on age." This addition regarding a child's inability to sit unaided focuses on faulty beliefs regarding the quality of an individual's life rather than their likely response to treatment.⁵ The ADA specifically meant to ensure people with disabilities were not subjected to enshrined discrimination based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living.⁶ Unfortunately, this policy codifies these unwarranted assumptions.

In addition to explicitly naming certain conditions for potential exclusion from care, Utah's Crisis Standards of Care Guidelines also implicitly disadvantage and deprioritize nearly any person with a disability. The Guidelines are premised upon a "scoring system" that consists of three categories including age, ASA score and estimated

³ https://coronavirus.utah.gov/wp-content/uploads/Final_Utah_Crisis_Standards_of_Care_011719-1.pdf at 30-31

⁴ *Id.*

⁵ *Id.* at 34.

⁶ H.R. Rep. No. 101-485, pt. 3, at 31-32 (1990); <https://www.congress.gov/congressional-report/110th-congress/house-report/730/2>

survival. Each category can allot up to 3 points for a continuous scale of 1-9. Individuals with a score of 1-5 receive a high priority for treatment while individuals with a score of 6-7 will be a lower priority and an individual with a score of 8-9 will simply not be treated if resources are insufficient.⁷ The “ASA score” is essentially a stand-in for pre-existing medical condition or disability. The State’s guidelines support this conclusion by detailing that “the ASA score is based on the American Society of Anesthesiologists Physical Classification System. It is included as a marker for increased comorbid illness and thus a trend toward greater resource utilization.”⁸

The Guidelines go on to state that an “ASA score of 1 is a healthy individual. ASA score 2 is mild and controlled systemic disease, without functional impairment...and an ASA score 3 is severe or uncontrolled systemic disease which has led to functional impairment.”⁹ Similar to the focus on assistance with activities of daily living, is the ASA’s inclusion of “functional impairment.” Without any additional guidance or clarification on how a functional impairment is to be factored in, physicians could see an individual who is blind, or uses a wheelchair as potentially deserving a higher ASA score because they may perceive such individuals as having a “functional impairment.” There is no need for the inclusion of the ASA score in Utah’s Patient Prioritization Tool, and it will have the effect of unlawfully disadvantaging many Utahns with disabilities.

On March 28, 2020, the Office of Civil Rights at Health and Human Services issued a bulletin directing covered entities not to discriminate against individuals with disabilities when developing protocols for the COVID-19 pandemic. Specifically, the directive stated, “decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”¹⁰ Since its release, national advocacy groups offered guidance on the way in which this bulletin should be implemented emphasizing the need for vigilance regarding discrimination and a rejection of disability-based quality of life stereotyping.¹¹ Utah’s Guidelines simply do not meet this standard. As the attached Complaint filed with your office by Washington and national disability advocacy groups points out in detail, federal law prohibits public and private actors from discriminating against people with disabilities. Doing so is nothing short of a clear violation of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. We therefore request that OCR immediately investigate and resolve this complaint of disability

⁷ https://coronavirus.utah.gov/wp-content/uploads/Final_Utah_Crisis_Standards_of_Care_011719-1.pdf
pp 29

⁸ *Id.* at 27.

⁹ *Id.* at 29

¹⁰ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

¹¹ https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf

discrimination, and promptly detail what Utah 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.

Please contact Laura Henrie, Associate Legal Director, with any questions or responses to this complaint at lhennie@disabilitylawcenter.org.

Sincerely,

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Attachment A



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://nwahrn.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,

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