PRESS RELEASE

Disability discrimination complaint filed over COVID-19 treatment rationing plan in Washington State

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SEATTLE – 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.

Self Advocates in Leadership (SAIL), Disability Rights Washington (DRW), and The Arc of the United States (The Arc) <u>filed a complaint</u> with the U.S. Department of Health and Human Services Office of Civil Rights (OCR) about their grave concerns that the plans being put in place discriminate 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) and place their lives at serious risk. We call for OCR to take immediate action to address this discrimination and assist local jurisdictions and providers to develop non-discriminatory approaches before there are lethal consequences to application of these illegal policies.

The complaint focuses specifically on the plan released Friday by the Washington Department of Health and the Northwest Healthcare Regional Network that even those who developed the plan admit "is not going to be pretty."

"I know already that intellectually disabled people get denied care because of being seen as lacking value," said Ivanova Smith, Chair of Self Advocates in Leadership and individual complainant in the letter filed today with HHS OCR. "I deserve the same rights as anyone else. These policies discriminate against me and put my life at risk."

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.

A Seattle area patient of the University of Washington Medical Center explained that "I am concerned that a doctor will see my diagnosis of cystic fibrosis in my chart and make lots of erroneous assumptions about me. Cystic fibrosis often comes with significant breathing difficulties and a life expectancy of 30 years," said Rose, not her real name due to fear of retaliation. "However, tests show that I have better breathing capacity than most people without cystic fibrosis and although I'm 28 years old, I have never been hospitalized and I am not anywhere close to dying. If I get COVID-19 and need intensive treatment like a ventilator, I fear the person making decisions about who gets treatment and who doesn't will see my file among dozens or even a hundred or more people all competing for limited spots and my diagnosis will stand out and be used to exclude me from getting treatment despite what my individual medical tests and record say."

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.

"The disability community is a broad, inclusive community where individuals with a variety of unique life experiences join forces to fight the many ways they are similarly discriminated against. We will not sit by as members of our community are left for dead. We stand up for those with preexisting disabilities and those with newly acquired disabilities who are impacted by COVID-19. We implore OCR to rein in and provide urgently needed guidance to the health care professionals who are prepared to relegate members of our community to die," said David R. Carlson, Director of Advocacy, Disability Rights Washington.

"As COVID-19 sweeps our country, we are reminded once again that for far too long, the lives of people with disabilities have been undervalued. It is cruel that a person with a disability seeking medical treatment during this pandemic may not receive the care they need or they may be left to suffer or die because they are seen as less than or other. It is urgent that the federal government make very clear right now, on the front end of this health emergency, that it will swiftly enforce federal laws that protect against medical rationing plans discriminating against people with disabilities. We know this is just the beginning, and that there are many more days and months to come. The federal government must get it right, now, from the start. The lives of millions of people with disabilities across the nation are at stake – and those lives do have value," said Peter Berns, CEO, The Arc.

The complaint stresses that 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 request that you enforce the obligations of the healthcare professionals in Washington to develop non-discriminatory approaches to the delivery of care before it is too late."

"Even in the midst of the current crisis, Washington State must abide by its obligation to not discriminate against people with disabilities. The complainants are on the front lines of a vital civil rights struggle. Their lives are at stake. I urge the HHS Office of Civil Rights to take swift

action to protect them," said Ari Ne'eman, Visiting Scholar with the Lurie Institute for Disability Policy at Brandeis University.

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