

PRESS RELEASE

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

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NASHVILLE - As COVID-19 cases increase, the experience in other countries and predictions of United States 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 U.S. 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.

Disability Rights Tennessee (DRT), The Arc Tennessee (The Arc TN), and several other disability advocacy organizations filed on behalf of their constituents and several individual Complainants a complaint with Tennessee's Office of Civil Rights (OCR) on Friday, March 27, 2020 about Tennessee's Guidance for the Ethical Use of Scarce Resources during a Health Emergency.

The complaint voices grave concern 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. Complaints have called upon the 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 ADA, Section 504, and Section 1557 cover the state of Tennessee and all Tennessee hospitals, health care providers, health plans and insurers. These federal laws prohibit disability discrimination in medical decision-making. The attached complaint filed today by Disability Rights Tennessee and others details these principles.

Yet Tennessee's 2016 "Guidelines for the Ethical Allocation of Scarce Resources"¹ 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.

Jean Marie Lawrence is a Tennessean who 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, 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."

Jean Marie story is just one example 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.

It has been requested 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.

Given that the pandemic is spreading at a rapid pace and the number of confirmed cases and deaths is climbing each day, this is a topic requiring immediate attention.

Complainants are represented by their counsel who are available for comment:

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Self-Advocates and family members available for comment. Personal contact information available upon request.

Jean Marie Lawrence
Self-Advocate

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

Erin Brady Worsham

Self-Advocate

Erin's biography is attached in a separate document.

Jennifer Aprea

Mother

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.