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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.