April 8, 2020

To: The State Disaster Medical Advisory Committee

From: Lisa Pugh, The Arc Wisconsin

Re: Preventing disability discrimination in COVID-19 treatment rationing

The Arc Wisconsin supports people with intellectual and developmental disabilities (I/DD) and their families. Since 1960, The Arc Wisconsin has served individuals and their families through our 14 locally affiliated chapters across the state. Our mission includes influencing public policies and promoting that all people with intellectual and developmental disabilities are entitled to the respect, dignity, equality, safety, and security accorded to other members of society, and are equal before the law.

We recognize the importance and gravity of the work you are doing to ensure the health and safety of Wisconsin citizens and specifically to guide our healthcare system in decisions related to life-saving treatment and the allocation of scare resources during a public health emergency.

We write to ask that Wisconsin’s crisis standards of care specifically acknowledge federal disability rights laws—including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. These laws broadly protect people with disabilities against discrimination in receiving medical treatment. The laws apply to hospitals experiencing a medical equipment, bed, or staffing shortage during the COVID-19 pandemic as well as state policies concerning how resources should be allocated in the event of such shortages.

Unfortunately, we have seen other states adopt standards or guidance that do not respect the rights of individuals with disabilities. Those state policies are now being met with immediate legal complaints outlining the illegality of medical rationing based on disability.

The U.S. Department of Health and Human Services’ Office of Civil Rights (HHS OCR) published a bulletin on March 28, 2020 to ensure that covered entities follow civil rights laws. The guidance explains that entities funded by HHS cannot deny people with disabilities medical care “on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities.”

The Arc Wisconsin recommends that the State Disaster Medical Advisory Committee adopt and endorse guidance that specifically includes the principles issued in the document “Guidance to States and Health Care Providers On Avoiding Disability-Based Discrimination in Accessing COVID19 Treatment” issued April 3, 2020. This guidance was developed by the Center for Public Representation, The Arc, Bazelon Center, Autistic Self Advocacy Network, DREDF, and Professor Sam Bagenstos and endorsed by 90 national disability and healthcare advocacy organizations. It
explains how states and health care providers should interpret the OCR guidance and take concrete steps to modify policies and practices to avoid disability discrimination.

You can find the complete communication here: https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf

We reiterate that Wisconsin guidelines must not leave room for vague interpretations. As the OCR guidance clearly states: “[P]ersons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities. 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.”

We appreciate your support on this critical issue.

Regards,

Lisa Pugh
Executive Director