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Expanding Opportunities for Persons with Disabilities

April 14, 2020

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Governor of Florida
The Capitol
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GovernorRon.Desantis@eog.myflorida.com

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Secretary Barbara Palmer
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RE: Florida Policies Regarding Allocation of Scarce Resources, COVID-19

Dear Hon. DeSantis, Dr. Rivkees, President Stickle, Dr. Goodman, Sec. Mayhew and Sec. Palmer:

We are organizations and networks representing the over two million Floridians with disabilities and chronic medical conditions. We write with great urgency and grave concern regarding the Ethics Guidelines for Crisis Standards of Care in Public Health Emergencies published by the Florida Bioethics Network (Guidelines) on April 8, 2020, and cited with approval by the Florida Hospital Association on April 9, 2020.

The lives of people with disabilities are equally worthy and valuable as those of people without disabilities. Under state and federal laws, people with disabilities must have an equal opportunity to receive life-sustaining treatment during the COVID-19 pandemic. But the FBN Guidelines direct the denial of care to countless disabled individuals who could benefit from treatment and survive hospitalization.

Pursuant to the recent guidance by the U.S. Department of Health and Human Services on COVID-19, dated March 28, 2020 – “Persons 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 or Age.” Furthermore, the Director of HHS Office of Civil Rights, Roger Severino, stated, ““Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism,”

We call on the State of Florida and medical stakeholders to reject disability discrimination in the allocation of scarce resources during COVID-19.

Life Expectancy, “Long Term Prognosis,” and “Life Years”

The FBN Guidelines state that priority in ventilator allocation and “reallocation” should be given to those who are most likely to “live longest in the community” after discharge. FBN Guidelines at 12. They state that ventilator triage should seek to save “the most life-years.” Guidelines at 13. They describe a scoring system for triage that includes “long term prognosis.” Guidelines at 14.

The use of life expectancy, long term prognosis, or “life years” as a basis for exclusion from treatment during COVID-19 discriminates against people with disabilities who have or who are thought to have a shortened life expectancy due to their disabilities. Such individuals include people with cystic fibrosis, spinal muscular atrophy, ASL, kidney disease, and metastatic cancer. People with these and other disabilities regularly outlive the prognoses that doctors ascribe to them, often by decades. Moreover, having disability diversity is valuable and essential to our society, even if some people with disabilities do not live as long. People with disabilities make unique contributions – including to developing the systems of care we need during a public health crisis.

The American College of Physicians recognized this in their March 26, 2020 resolution, which states: “Allocation of treatments must maximize the number of patients who will recover, not the number of “life-years,” which is inherently biased against the elderly and the disabled.” American College of Physicians, Non-Discrimination in the Stewardship and Allocation of Resources During Health System Catastrophes Including COVID-19, at https://www.acponline.org/acp_policy/policies/acp_policy_on_non-discrimination_in_the_stewardship_of_healthcare_resources_in_health_system_catastrophes_including_covid-19_2020.pdf.

The undersigned reject the use of life expectancy and “life years” as a basis for allocating scarce resources such as ventilators during COVID-19. It is critical that any guidelines about allocating scarce resources during the pandemic direct an individualized assessment of whether the person can benefit from care and survive treatment. Such guidelines should not consider survival beyond

the immediate short term. Considerations of life expectancy, long term survival, and “life years” in coronavirus triage is an impermissible form of disability discrimination.

“Reallocation” of Ventilators

The FBN Guidelines discuss the “reallocation” of ventilators during COVID-19 at certain points in time for patients who do not show certain levels of improvement. Guidelines at 12-17. This is also referred to in the Guidelines as “terminal extubation.” Guidelines at 13, 17.

Such a reallocation policy has a chilling effect on individuals with disabilities who utilize ventilators in their daily lives. Regular users of ventilators are afraid to seek medical help when they become ill because ventilator rationing may result in their every-day ventilators being re-allocated to other patients who are deemed a higher priority, with the result being death.

It is critical that any guidelines discussing the reallocation of ventilators make clear that doctors and triage teams may not “reallocate” the personal ventilators of disabled patients who use this equipment on a regular basis. These patients are entitled to continue to use their personal equipment if they receive COVID-19 treatment at a hospital.

Moreover, hospitals and other health care providers are required to make reasonable modifications in policies, practices, and procedures when needed by a disabled person to have an equal opportunity to benefit from the treatment. Some individuals may need a longer time on a ventilator to show improvement because of disability. Any guidelines setting out time intervals for ventilator assessment and reallocation should include the provision of a longer period of time as a form of reasonable modification for disability.

Assessments of “Long Term Prognosis” Based on “Comorbidities”

The FBN Guidelines describe a scoring system for triage that includes “long term prognosis” due to “comorbidities.” Guidelines at 13-15. Patients get points – and therefore a lower priority for treatment – for a lengthy list of medical conditions, including: cardiovascular disease, diabetes mellitus, chronic respiratory disease, hypertension, cancer, moderate dementia, cancer with less than a ten-year survival rate, heart disease, COPD, moderate lung disease, end stage renal disease, inoperable coronary artery disease, severe dementia, metastatic cancer, severe lung disease, cirrhosis, and traumatic brain disease with low motor response, and severe immunocompromised states.

All of the listed conditions are disabilities protected under state and federal laws. The fact that a patient has a particular diagnosis is not a permitted reason for denying care or making that person a lower priority to receive treatment. Doctors must make an individualized assessment of whether the person can benefit from care and survive in the immediate short term. They must not assume that any specific diagnosis or disability automatically indicates a poor prognosis for near-term

survival or an inability to respond to and benefit from treatment. Many people living with the listed conditions outlive medical predictions by years. Some of the listed conditions, such as dementia and any form of cancer, have no clear connection to the ability to benefit from treatment and to survive in the short term.

It is critical that any guidelines adopted to allocate scarce resources do not disadvantage individuals with particular diagnoses who can benefit from treatment and survive. All people with disabilities are entitled to receive lifesaving care, unless it is medically clear that the person will not survive in the immediate term or that the treatment is contra-indicated.

Assessments Based on SOFA Scores

The FBN Guidelines describe a scoring system for triage that includes short-term prognosis based on SOFA (Sequential Organ Failure Assessment) scores. Guidelines at 13-15. SOFA scores may discriminate if people with disabilities, such as a chronic condition requiring daily ventilator use, start with a higher baseline score due to pre-existing conditions. SOFA standards may also misconstrue disability-related characteristics. A person with a speech disability could receive a higher SOFA score if they cannot give a verbal response.

It is critical that any guidelines endorsing a scoring system like the SOFA include reasonable modifications to ensure that the score reflects an objective assessment of whether an individual can benefit from treatment and survive in the short term.

Appeal Process for Ventilator Removal

The FBN Guidelines describe a “limited” appeal process for ventilator removal that “might not happen.” Guidelines at 18. The undersigned seek a robust appeal process for ventilator removal as such action ends life. The process must be explained and available to all patients. Such a process should include a referral to Disability Rights Florida.

Priority for Individuals Who Perform Tasks Supporting Acute Care

The FBN Guidelines recommend that priority in tie-breakers for allocating scarce resources be given to those who directly support acute care. We believe that if this type of priority is adopted, then individuals who keep disabled individuals safe in their homes, including personal care attendants and home health care providers, should also be given priority. These essential workers help keep disabled people away from the hospital and the prospect of health care rationing.

In conclusion, urge you to act immediately to include the interests and needs of the disability community in planning for COVID-19. It is critical that any guidelines or policies for the allocation of scarce resources in Florida during COVID-19 focus on the ability to benefit from and survive

treatment, rather than myriad traits and statuses that are proxies for disability. We urge you to reject the FBN Guidelines as they are currently drafted. These are matters of life and death for us.

To discuss these concerns further, please contact Matthew W. Dietz at mdietz@justdigit.org or at (305) 669-2822, who can set up a meeting with community representatives.

Sincerely,

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