





North Carolina Increases COVID-19 Medical Rationing Protections for Disabled Patients in Response to Civil Rights Complaint by Disability Rights NC, Other Advocacy Groups

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The US Department of Health & Human Services Office for Civil Rights (OCR) resolved a federal complaint filed by Disability Rights North Carolina (DRNC) and The Arc of North Carolina alleging that North Carolina's scarce medical resource plan illegally deprioritized people with disabilities in the allocation of lifesaving care. DRNC and The Arc of North Carolina were joined by a coalition of national disabilities advocates who have filed more than a dozen such complaints since the pandemic began.

Partners in the NC case are the Center for Public Representation, The Arc of the United States, Bazelon Center for Mental Health Law, Autistic Self Advocacy Network and Samuel Bagenstos. Medical rationing policies have disproportionately impacted Black people with disabilities, because they have higher rates of COVID-19 infection and hospitalization.

In response to the complaint and engagement with OCR, North Carolina has revised its "Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic" to comply with federal disability rights laws and ensure that people with disabilities will not encounter discrimination even when public health emergencies, such as the COVID-19 pandemic, necessitate the rationing of medical resources.

"These changes will ensure that North Carolinians with disabilities have a fair chance to access lifesaving care if availability is limited. The disability community understands that extreme circumstances call for hard decisions, but these life-and-death choices must be made on the basis of individual medical realities, not stereotypes," said Larkin Taylor-Parker, a staff attorney at DRNC. "Our hope is that this policy helps ensure that resources are fairly distributed and not based on bias."

The following are key changes in North Carolina's policy to avoid discrimination against people with disabilities:

• **No Long-Term Survivability Considerations:** Scarce medical resources can no longer be allocated based on patients' perceived chances of long-term survival. Instead,

prioritization is based on patients' likelihood of surviving to discharge. Long-term survivability is uncertain. As such, it is fraught with speculation, stereotypes, implicit bias, and assumptions about the quality of life and lifespan of people with disabilities.

- Reasonable Modifications Required: North Carolina's Protocol now requires hospitals to make reasonable modifications to the Sequential Organ Failure Assessment (SOFA)

 the tool used to prioritize access to medical treatment —to avoid penalizing people with underlying conditions that are unrelated to their ability to benefit from treatment.
- Reallocation of Personal Ventilators Prohibited: Medical personnel may not reallocate the personal ventilator of a patient who uses a ventilator in their daily life to another patient whom the personnel deem more likely to benefit from the ventilator in receiving treatment.
- Effective Communication Required: Medical personnel must provide effective communication to patients and patient representatives who have disabilities or limited English proficiency as required by federal law.
- Blanket Do Not Resuscitate Orders (DNRs) Prohibited: Providers may not address resource constraints through blanket DRN orders.

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About Bazelon Center for Mental Health Law

The Judge David L. Bazelon Center for Mental Health Law advocates for the civil rights, full inclusion and equality of adults and children with mental disabilities. We were pivotal in expanding the civil rights movement to include fighting discrimination against, and segregation of, people with mental disabilities. The Bazelon Center uses a unique combination of litigation, public policy advocacy, coalition building and leadership, public education, media outreach and technical assistance—a comprehensive approach that ensures we achieve the greatest impact. Learn more about the Bazelon Center at bazelon.org.

About Disability Rights North Carolina

Disability Rights North Carolina is the federally mandated protection and advocacy system in North Carolina, dedicated to advancing the rights of all people with disabilities, of all ages, statewide. DRNC is an independent, 501(c)(3) nonprofit organization and a member of the National Disability Rights Network. Learn more about Disability Rights North Carolina at disabilityrightsnc.org.

About The Arc of North Carolina

The Arc of North Carolina is committed to securing for all people with intellectual and developmental disabilities the opportunity to choose and realize their goals of where and how they learn, live, work and play. The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and

participation in the community throughout their lifetimes. Learn more about The Arc of North Carolina at <u>arcnc.org</u>.

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