



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office for Civil Rights

Eastern & Caribbean Region
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June 15, 2022

VIA EMAIL ONLY (gorlowski@disabilityrightnj.org & mciccone@disabilityrightsnj.org)

Gwen Orlowski, Executive Director & Mary Ciccone, Director of Policy
Disability Rights New Jersey
210 South Broad Street, Third Floor
Trenton, New Jersey 08608

OCR Transaction Number: 22-465160

Dear Gwen Orlowski & Mary Ciccone:

On January 23, 2022, the U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR), received your complaint against the New Jersey Department of Health (NJDOH). OCR has reviewed your allegations and determined to resolve your complaint with the provision of technical assistance to the NJDOH.

If you have any questions regarding this matter, please contact me at (212) 264-4136 or Linda.Colon@hhs.gov. When contacting this office, please remember to include the transaction number that we have given this file.

Sincerely,

Linda C. Colón
Regional Manager

Enclosure: Copy of OCR's Letter to the NJDOH



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VIA EMAIL (Francis.Baker@law.njoag.gov) AND REGULAR MAIL

Francis X. Baker, Deputy Attorney General
Health & Human Services Section
Office of the New Jersey Attorney General
R.J. Hughes Justice Complex
25 Market Street, P.O. Box 112
Trenton, New Jersey 08625

OCR Transaction Number: 22-465160

Dear Francis X. Baker:

On January 23, 2022, the U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR), received the above-captioned complaint alleging that the New Jersey Department of Health (NJDOH) is not compliant with Section 504 of the Rehabilitation Act (Section 504),¹ Title II of the Americans with Disabilities Act (Title II of the ADA),² and Section 1557 of the Affordable Care Act (Section 1557).³

Specifically, Disability Rights New Jersey (the complainant) alleges that the NJDOH's critical resource allocation policy, titled "Allocation of Critical Care Resources During a Public Health Emergency," published on April 11, 2020, and amended on December 16, 2020 (the Allocation Policy),⁴ could result in unlawful discrimination on the basis of disability by health care facilities in New Jersey.

OCR enforces civil rights laws which prohibit discrimination in the delivery of health and human services based on race, color, national origin, disability, age sex, religion and the exercise of conscience, and also enforces the Health Insurance Portability and Accountability Act (HIPAA) Privacy, Security and Breach Notification Rules.

¹ 29 U.S.C. §§ 794, *et seq.*, as implemented by 45 C.F.R. Part 84.

² 42 U.S.C. §§ 12131, *et seq.*, as implemented by 28 C.F.R. Part 35.

³ 42 U.S.C. § 18116, as implemented by 42 C.F.R. Part 92

⁴ <https://nj.gov/health/legal/covid19/AllocationMemoRevised.pdf>

OCR is responsible for enforcing Section 504 as it applies to entities that receive Federal financial assistance (FFA) from HHS. Section 504 prohibits discrimination on the basis of disability by recipients of FFA and applies to all of the recipient's programs and activities. OCR is also responsible for enforcing Section 1557 as it applies to the health programs and activities of recipients of FFA. Section 1557 prohibits discrimination on the basis of disability in all of the operations of entities principally engaged in the business of providing healthcare that receive FFA. Section 1557 also prohibits discrimination on the basis of disability in health program or activity operations of entities not principally engaged in the business of providing healthcare to the extent that the specific health program or activity operation receives FFA. OCR is also responsible for enforcing Title II of the ADA as it applies to the provision of health care and social services by public entities. Title II of the ADA prohibits discrimination on the basis of disability in all services, programs, or activities of state and local governmental agencies and their political subdivisions.

Specifically, Section 504, Section 1557, and Title II of the ADA require covered entities to ensure that an individual with a disability has the opportunity to participate in or benefit from the covered entity's services, programs, and activities for which the individual meets the essential eligibility requirements.⁵ In providing such an opportunity to participate in the covered entity's programs, services, or activities, the covered entity must make reasonable modifications to its programs, services, or activities unless the covered entity can demonstrate that the modification would fundamentally alter the nature of the covered entity's programs or activities.⁶ Failure to make such reasonable modifications may discriminate against individuals with disabilities.

OCR has reviewed NJDOH's Allocation Policy and notes the following concerns: The Allocation Policy deprioritizes patients with disabilities believed to impact long-term survival. The Allocation Policy also provides protections against re-allocation of personal ventilators for *adult* chronic ventilator users, but does *not* extend these protections to *pediatric* chronic ventilator users. Further, the Allocation Policy does not explicitly provide for reasonable modifications to the use of clinical instruments (e.g., Sequential Organ Failure Assessment (SOFA)) for assessing likelihood of short-term survival when necessary for accurate use with patients with underlying disabilities. Also, with respect to the use of therapeutic trial protocols for mechanical ventilation, the Allocation Policy does not articulate reasonable

⁵ See 45 C.F.R. §§ 84.4(b)(1) and 84.52(a); 45 C.F.R. §§ 92.2(a) and (b); and 28 C.F.R. §§ 35.130(b)(1)(i) and (ii).

⁶ See 45 C.F.R. §§ 84.4(b)(1) and 84.52(a); 45 C.F.R. §§ 92.2(a) and (b); and 28 C.F.R. §§ 35.130(b)(1)(i) and (ii).

modifications to permit some additional time when necessary to evaluate effectiveness for individuals with disabilities.

Pursuant to regulations at 45 C.F.R. § 84.61, Section 504 incorporates the procedural provisions of Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d et seq., and its implementing regulations, which provisions include that OCR “shall to the fullest extent practicable seek the cooperation of recipients in obtaining compliance ... and shall provide assistance and guidance to recipients to help them comply voluntarily....” 45 C.F.R. § 80.6(a).

Accordingly, OCR has determined to resolve this matter through the provision of technical assistance to NJDOH.

Section 504, Title II of the ADA and Section 1557 ensure that individuals with disabilities are not excluded from participation in, or denied the benefits of, services, programs, or activities, or otherwise subjected to discrimination, on the basis of disability and have an opportunity to participate in, or benefit from, services equal to that afforded others. These services, programs, or activities must be accessible and usable by individuals with disabilities.

Stereotypes, bias and quality of life judgments

When allocating scarce resources or care in a public health emergency, covered entities must analyze the specific patient’s ability to benefit from the treatment sought, free from stereotypes and bias about disability, including prejudicial preconceptions and assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities.⁷

Bias refers to an unfavorable perception based on prejudice, assumptions, conclusions or beliefs about an individual or group of individuals with a specific disability or any disability that is not supported by current medical knowledge or the best available objective evidence. Use of assessment tools or factors for making resource allocation decisions that screen out or tend to screen out individuals with disabilities or any class of individuals with disabilities from fully and equally enjoying any healthcare service, program, or activity being offered, unless such criteria can be shown to be necessary

⁷ See HHS OCR Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) (Mar. 28, 2020), <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf> - PDF.

for the provision of the service, program or activity being offered, would violate nondiscrimination laws.⁸

Categorical exclusions on the basis of disability

Categorical exclusions in Crisis Standards of Care that deny critical healthcare services to individuals based solely on the type of disability an individual has, when treatment would not be futile for individuals with that type of disability, violate disability rights laws. For example, a hospital is prohibited from having a categorical exclusion denying life-saving care to individuals with Down syndrome based on a judgment that people without Down syndrome would be a greater benefit to society or would experience a richer or fuller life than those with Down syndrome.

Resource allocation decisions

While covered entities may rely upon applicable Crisis Standards of Care in making resource allocation decisions that affect individuals with disabilities, those standards should be based on current medical knowledge or the best available objective evidence regarding effectiveness of treatment. To avoid disability discrimination, Crisis Standards of Care should be applied in a way that assesses whether the treatment sought is likely to be effective for each individual patient. Hospitals may, however, deny care during a public health emergency on the basis that such care is unlikely to be effective for a particular patient, after analyzing that patient's ability to respond to the treatment being sought. The patient's pre-existing disability or diagnosis should not form the basis for decisions regarding the allocation of scarce treatment, unless that underlying condition is so severe that it would prevent the treatment sought from being effective or would prevent the patient from surviving until discharge from the hospital or shortly thereafter. Further, when mortality predictions are based on a patient's underlying disability, and not the condition for which they need immediate care, the less grounded in objective medical evidence they are likely to be, as critical care providers are not likely to have expertise concerning the life expectancy of every underlying condition patients have.

Reasonable modifications for individuals with disabilities

In addition, Section 504 and Section 1557 require covered entities to make reasonable modifications to policies, practices and procedures where necessary to provide individuals with disabilities an equal opportunity to participate in covered health programs and activities, unless the

⁸ 28 C.F.R. § 35.130(b)(8).

modifications would work a fundamental alteration in the nature of the health program or activity or impose an undue financial and administrative burden.

If, as part of its Crisis Standards of Care, a hospital is using an assessment tool that unnecessarily screens out, or tends to screen out, individuals with disabilities from the opportunity to benefit from an aid, benefit, or service, and alternative tools are not available, a hospital may need to make a reasonable modification in its use of the assessment tool unless doing so would cause a fundamental alteration or impose an undue financial and administrative burden. For example, the Glasgow Coma Scale considers whether a person's speech is comprehensible and whether they obey commands for movement. Someone with cerebral palsy may have difficulty speaking or moving as part of their underlying disability, which is not the condition that caused them to seek treatment at a hospital. Adjustments must be made to ensure that such a person's pre-existing condition, and the symptoms of that condition, are not considered when using the Glasgow Coma Scale to evaluate whether they qualify for treatment. Similarly, a covered entity may need to make reasonable modifications for individuals with disabilities when evaluating the effectiveness of a treatment. For example, in evaluating the effectiveness of ventilator treatment, a covered entity may need to allow an individual with a disability some additional time on a ventilator to assess likely clinical improvement, unless doing so would constitute a fundamental alteration of the ventilator trial or impose an undue burden.

OCR's guidance on crisis standards of care and related frequently-asked-questions are included in the links below:

<https://www.hhs.gov/about/news/2021/01/14/ocr-provides-technical-assistance-ensure-crisis-standards-of-care-protect-against-age-disability-discrimination.html>

<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/disability-faqs/index.html>

You are encouraged to review these materials closely to ensure NJDOH, through its Allocation Policy, does not promote practices by health care facilities which could violate applicable nondiscrimination laws.

You are also encouraged to assess and determine whether there may have been an incident of noncompliance as alleged in the complaint, and if so, to take the steps necessary to remedy the noncompliance and ensure it does not occur in the future. Should OCR receive a similar allegation of

noncompliance against NJDOH in the future, OCR may initiate a formal investigation of that matter. In addition, please note that OCR may initiate and conduct a compliance review of NJDOH.

Based on the foregoing, OCR is closing this case without further action, effective the date of this letter. OCR's determination as stated in this letter applies only to the allegations in this complaint that were reviewed by OCR.

If you have any questions regarding this matter, please contact me at (212) 264-4136 or Linda.Colon@hhs.gov.

Sincerely,

A handwritten signature in dark ink, appearing to read "Linda C. Colón", followed by a horizontal line.

Linda C. Colón
Regional Manager

cc: Gwen Orlowski, Executive Director, Disability Rights New Jersey
Mary A. Ciccone, Director of Policy, Disability Rights New Jersey
(via email only, gorlowski@disabilityrightsnj.org and
mciccone@disabilityrightsnj.org)