



National
Kidney
Foundation™

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November 6, 2015

The Honorable Sylvia Mathews Burwell
Secretary of Health and Human Services
200 Independence Avenue SW
Washington, D.C. 20201

Jocelyn Samuels
Director
Office for Civil Rights
Attention: 1557 NPRM (RIN 0945-AA02)
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: RIN Number 0945-AA02: Nondiscrimination in Health Programs and Activities
Proposed Rule

The National Kidney Foundation (NKF) strongly supports this proposed rule and encourages the Office of Civil Rights (OCR) to finalize it with some clarifications outlined in in this letter. NKF has been a strong supporter of the Affordable Care Act's (ACA) provisions that have allowed those with chronic conditions to gain access to the health insurance they need to get appropriate care and medications. We appreciate that this rule prohibits discrimination in the health system on the basis of race, color, national origin, sex, age, or disability. NKF is America's largest and oldest health organization dedicated to the awareness, prevention, and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of people at risk. In addition, NKF has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI).

Clarification on definition of disability

Section 1557 of the ACA refers to several statutes to help define discrimination based on race, color, national origin, sex, age or disability. Specifically for disability the ACA refers to section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794). HHS interprets and describes disability under this Act as the following:

... persons with a physical or mental impairment which substantially limits one or more major life activities. People who have a history of, or who are regarded as having a physical or mental impairment that substantially limits one or more major life activities, are also covered. Major life activities include caring for one's self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning. Some examples of impairments which may substantially limit major life activities, even with the help of medication or aids/devices, are: AIDS, alcoholism, blindness or visual impairment, cancer, deafness or hearing impairment, diabetes, drug addiction, heart disease, and mental illness.¹

Individuals with end-stage renal disease (ESRD) and who are on dialysis, been on dialysis or who have a kidney transplant meet this definition. However, to avoid confusion we request that this final rule specify that disability includes those with ESRD as well as other chronic conditions.

Clarification on Discriminatory Acts

NKF has identified some health insurance plans with medical and drug benefit designs that specifically shift a higher portion of health care costs to individuals with ESRD, sometimes in an effort to coerce ESRD patients into Medicare. In regards to dialysis patients, we have identified cases where patients have been contacted by their plan and told they must, or in some cases should, enroll in Medicare. Some plans have even gone so far as to limit coverage, to pay only secondary benefits, or to set limits on how much the plan will pay for dialysis treatments – subjecting patients to balance billing that does not count towards their out-of-pocket maximums. While ESRD patients are eligible for Medicare they are not required to enroll. HHS has issued guidance clarifying (through an ACA frequently asked questions document) this and that plans may not limit coverage or benefits due to a patient's health status. While §92.207(b) of this rule mentions that plans shall not (1) deny or limit coverage of a claim, or impose additional cost sharing or other limitations or restrictions, on the basis of an enrollee's or prospective enrollee's race, color, national origin, sex, age, or disability; (2) employ marketing practices or benefit designs that discriminate on the basis of race, color, national origin, sex, age, or disability in a health-

¹ <http://www.hhs.gov/ocr/civilrights/resources/factsheets/504.pdf>

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related insurance plan or policy, or other health care system, given the uniqueness of the Medicare program for ESRD patients, we believe there is a lack of understanding across states and plan issuers that this practice is indeed discriminatory and therefore request the specific ESRD language also be included in the final rule.

In addition, NKF has identified incidences in some Marketplace plans where immunosuppressive drugs, including generics, are placed on the highest cost-sharing tier. We appreciate that HHS has issued guidance that placing all medications to treat a chronic condition on the highest tier could be considered discriminatory. However, we believe the final rule should include definitive language that this is an example of discrimination.

Establish a federal complaint and oversight process

NKF supports and appreciates the oversight and enforcement requirements set forth in the proposed rule. However, NKF encourages OCR to also establish a process whereby beneficiaries (and/or their advocates), who believe they have been discriminated against based on their disability, can submit grievances directly to OCR and have those reports and the results of the investigation made publicly available. This will ensure there is consistent oversight and enforcement across the U.S. and protect beneficiaries equally no matter where they reside.

Sincerely,

Tonya L. Saffer

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Senior Health Policy Director