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National Advocacy

29 National Patient & Consumer Organizations Condemn Administration’s Final Rule on Nondiscrimination Provisions in Health Care Law

In June 2019, the U.S. Department of Health and Human Services (HHS) proposed changes to the rules implementing and weakening Section 1557 of the Affordable Care Act (ACA). Section 1557 prohibits discrimination based on race, color, national origin, sex, age, and disability in health care programs and activities operated or funded by the federal government. In August 2019, the Epilepsy Foundation, along with hundreds of national patient, disability, and consumer groups, urged the Administration to withdraw the proposed change.
On June 12, 2020, HHS finalized the new rule which attempts to undermine critical patient protections by significantly weakening and in part eliminating the enforcement of health care nondiscrimination provisions. The Epilepsy Foundation joined 28 national patient and consumer organizations in condemning the Administration’s final rule. The elimination of these important protections will result in severe consequences for the health and well-being of millions of Americans seeking health care, especially those with serious, acute, chronic or other pre-existing conditions and those in vulnerable and under-served communities.

Hospital Visitor Policies Nationwide Must Accommodate Patients with Disabilities During COVID-19 Pandemic

On June 9, 2020, in response to the first federal complaint challenging discriminatory hospital no-visitor policies during the COVID-19 pandemic, the State of Connecticut issued an executive order to ensure that people with disabilities will be able to be accompanied by their support person/aid during hospital, acute care and other medical care visits. The executive order resolves complaints that had been filed by disability groups with the Office for Civil Rights (OCR) at HHS. With the resolution, and the resulting new Connecticut policy, OCR has made clear its expectations for how states and hospitals nationwide can both safeguard public health and adhere to their legal and ethical obligations.

Additionally, the State of California Department of Public Health sent an update to their Visitors Limitations Guidance clarifying that patients who need a support person/aid in order to receive equal medical treatment can be accompanied by those individuals even where other visitors would be excluded. The Foundation will continue to monitor issues of discrimination – from care rationing to hospital visitor policies and beyond – as the public health emergency persists.

State Advocacy

California Proposed Budget Cuts Critical Disability Services

In response to COVID-19 and the economic downturn, many state legislatures have resumed only to pass budgets and cut costs. In California, Governor Newsom proposed $500 million in cuts to vital disability support services in the May budget revision. We want to thank the grassroots advocates who took action and sent almost 500 letters to the Governor and their state elected officials urging them to reject the cuts and pass an alternative budget plan that keeps disability services a priority throughout the budget process. A
tentative deal may have been reached between the Governor and state lawmakers regarding cuts to Medi-Cal recipients, In Home Supportive Services and child-care providers. We will continue to monitor the situation and keep Californians apprised of the decision.

We encourage you to invite others to join our Speak Up, Speak Out! advocacy network. Members receive the monthly Capitol Circuit newsletter and alerts about opportunities to advocate for the epilepsy community throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we move through busy state and federal legislative sessions. Make a difference today by sharing our Speak Up, Speak Out! Network on Facebook and Twitter.

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