



The Capitol Circuit

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National Advocacy

Congressional and Administrative Stalemate on Legislative Activity

Congress is officially on August recess meaning that Representatives and Senators have left Washington, D.C. and are in their home state or district for a chance to spend time in their communities and hear from constituents, albeit virtually due to the pandemic. Members of Congress left the nation's capital without a deal on the next COVID-19 relief package, but Senate Republicans released a small COVID-19 package shortly thereafter. This smaller package includes provisions which would undermine employment protections for people with disabilities under the Americans with Disabilities Act (ADA). [The Epilepsy Foundation joined disability community leaders in expressing concerns over these provisions when they were first introduced in July.](#) It is unclear whether this will reignite negotiations and members are

on standby in case votes are called on the COVID-19 package or any other pressing issues.

Prior to leaving Washington, the U.S. House of Representatives passed a six-bill government funding “minibus” (H.R. 7617) at the end of July which encompassed Fiscal Year 2021 spending plans for various federal agencies. The mini package included funding for several programs important to the epilepsy community such as \$10.5 million for the Centers for Disease Control and Prevention (CDC)’s National Center for Chronic Disease Prevention and Health Promotion’s Epilepsy Program, which is the only public health program specifically related to epilepsy that offers a national scope and community programs.

While the Senate is not expected to begin working on their annual spending bills until after August recess, the \$1 million increase from the House for the CDC’s Epilepsy Program is positive and may be beneficial when it comes to the final spending bill. We are deeply grateful for the support from the community—both during the 2020 Teens Speak Up! Capitol Hill Day in March and for our grassroots sending a collective 2,450 letters to the U.S. House—that helped achieve this increase! Epilepsy Foundation local offices and advocates are holding virtual meetings with congressional offices during recess to thank the House for this progress and advocate for \$11.5 million for the CDC’s Epilepsy Program in the final spending package.

Epilepsy Foundation Releases 2019 Access to Care Survey and 2020 COVID-19 Survey Results

Access to affordable, quality, provider-directed and person-centered health care is critical for people with the epilepsies. In order to better understand what challenges—if any—people with the epilepsies are facing accessing the health care they need, the Epilepsy Foundation conducted a survey of our community in October 2019. With this data, we can start to better understand the experiences of people with the epilepsies, improve systems that connect people to epilepsy health care and advocate for improved access to care.

In addition to this survey, recognizing that the COVID-19 pandemic is impacting people with the epilepsies’ needs and how people are accessing health care, the Foundation sent an additional survey in April-May 2020 near the beginning of the COVID-19 pandemic to learn about potential emerging trends that could impact access to care.

[The highlights and full reports for 2019 Access to Care survey and the 2020 COVID-19 survey can be viewed here.](#)

Disability Community Unveils Telehealth Principles

During the COVID-19 pandemic, more and more Americans including people with the epilepsies have relied on telehealth visits to receive health care services. As we continue to face the pandemic and recover, policymakers are considering more permanent telehealth policies and hearing the benefits that telehealth visits provide many people with the epilepsies, the Foundation has supported the option to continue accessing care via telehealth. [In August, the Foundation as part of the Consortium for Citizens with Disabilities \(CCD\) unveiled a set of principles pertaining to telehealth](#) that will be used to gauge future legislative and regulatory proposals. The principles affirm that telehealth policies should improve health care services and access for people with disabilities and follow civil rights and patient privacy law.

State Advocacy

Oklahoma Pulls Back Harmful Medicaid Block Grant Proposal

Oklahoma officially withdrew its Medicaid block grant proposal following the approval of a ballot initiative earlier this summer expanding Medicaid to eligible adults. The SoonerCare 2.0 proposal would have greatly reduced the benefits of expansion and jeopardized beneficiaries' access to care. [The Foundation was strongly opposed to the state's Medicaid proposal and submitted a joint comment with the Epilepsy Foundation Oklahoma to Secretary Azar during the federal public comment period expressing our concerns](#). This is significant turn of events as Oklahoma was the first and only state so far to submit a proposal under the Administration's new block grant guidance and intended to serve as the "test case" for the policy. Halting these harmful cuts in Oklahoma could help preserve Medicaid in other states, particularly as the public health emergency persists and reliance on the Medicaid program remains significant.



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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