



AMERICAN

SOCIETY FOR

PEDIATRIC

RESEARCH

July 13, 2020

What Matters Now in Washington:

- Provider relief funds are now available for many pediatricians, though future financial relief and • policies to mitigate the COVID pandemic have yet to be determined by Congress. More...
- Racial justice has taken center stage after police brutality and the disproportionate impact of the COVID-19 pandemic on communities of color have increased the sense of urgency for action. More...
- Congressional appropriators have until September 30 to finish spending bills for the coming • year, but they face tight budget caps and an even tighter congressional calendar. More...
- COVID research in children continues to evolve while research for rare diseases takes a back seat. More...
- The decennial Census hit key targets for initial completion rates, setting the stage for in-person • field operations to reach as many Americans as possible. More...
- Recent Supreme Court decisions are legal victories for Dreamers and LGBTQ Americans. More...
- PPC members authored policy commentaries in *Pediatric Research* exploring the intersections of child health policy, advocacy, and pediatric research. More...

PEDIATRICIANS FINALLY ELIGIBLE FOR PROVIDER RELIEF AMID STALLED CORONAVIRUS

NEGOTIATIONS ON CAPITOL HILL. After months of delay, the Department of Health and Human Services (HHS) announced in early June that pediatricians would be able to apply for money through the Provider Relief Fund. The \$175 billion fund, appropriated by Congress in two COVID-19 response packages, is intended to offset lost revenue and non-reimbursable costs for expenses like personal protective equipment (PPE) for a health system that has been hit hard by the pandemic.

Despite broad recognition on Capitol Hill that the money was intended to provide immediate relief to hospitals, physician practices, and other health care providers, Congress failed to include a formula for how the funding was to be disbursed, leaving discretion to HHS leaders on how to get the money out quickly. As a result, HHS made distributions on the basis of Medicare billing, which fails to account for the vast majority of pediatricians. That decision left thousands of providers waiting months for needed relief and led to bipartisan outcry on Capitol Hill over the frontline providers who went without funds.

HHS's latest \$15 billion allocation from the fund is set aside for providers who bill Medicaid and the Children's Health Insurance Program. This means many pediatricians, pediatric medical subspecialists, and pediatric surgical specialists who have not already received funds are eligible to apply through an online portal until July 20. Qualifying practices can expect to receive a payment equal to at least 2 percent of reported gross revenues from patient care. While academic pediatricians are typically employed by academic medical centers that handle reimbursement, including applying for relief funds, smaller pediatric practices are essential to providing frontline care for children and triaging children with complex medical needs. This money will begin to address the challenges they've faced to stabilize a key element of pediatric care. Additional information on the Provider Relief Fund is available from the AAP.

-Impending Deadlines, Surging Case Counts May Drive Congressional Action on Next COVID-19

Package. In extraordinary fashion, Congress sped multiple major legislative packages across the finish line to aid families, the health care system, and businesses as the escalating toll of the pandemic came into stark relief earlier this year. After record spending to address the coronavirus, however, Congress

has come to a virtual standstill since the House of Representatives passed its fifth response package, the HEROES Act, in May. Since then, Congress has only managed to pass <u>minor technical fixes</u> to the Paycheck Protection Program, and the Senate does not plan to take up the latest House bill.

The delay has stemmed largely from a reticence among Republicans to continue spending and a belief that Congress needs more time to see the impact of its legislative initiatives to date, <u>limiting their sense</u> of <u>urgency</u>. That dynamic, though, may be changing. Much of the <u>emergency relief in the CARES Act</u>, including <u>enhanced unemployment benefits</u> and support for small businesses, is <u>winding down</u>, with some benefits ending on July 31. Additionally, cases of COVID-19 are rising in many places around the country in states like Florida, Texas, Arizona, and California following weeks of eased public health mandates and reopening policies.

With the sense of urgency building, Congress appears likely to aim for a major legislative package prior to the August recess, but roadblocks remain. Democrats have to date prioritized extending jobless benefits, funding for state and local governments, and health care infrastructure in future legislation. Republicans, on the other hand, have made clear that liability protections for businesses operating in the coronavirus era, more tailored economic stimulus for families, and policies aimed at getting children back to school will be essential. Given the scope of the federal relief provided to date, <u>Congress is certain to consider a broad range of policies</u> in its next COVID-19 relief bill.

-Health Care Stakeholders Outline Asks for COVID Relief. With Congress set to consider additional legislative relief, healthcare and research groups have staked out priorities for needed policy action as the fallout of the pandemic has brought about unanticipated consequences across the country.

The biomedical and scientific research community, for instance, is pushing for an infusion of supplemental funding for federal science funding agencies in upcoming legislation. While <u>federal</u> research support has been a critical lifeline for academic institutions to keep labs afloat, there is growing recognition that more funding is needed. <u>Champions for medical research on both sides of the aisle have introduced the Research Investment to Spark the Economy (RISE) Act</u> (H.R. 7308), which would provide \$26 billion for agencies like the National Institutes of Health (NIH) to ameliorate the disruption to federally funded research. This disruption has forced NIH and other agencies to fund unanticipated grant extensions, and researchers will face added costs moving forward to ramp up research capacity and conduct research safely. Absent additional federal support, some fear that resources intended for investments in other areas of science will be diverted to COVID-19 expenses. NIH would receive \$10 billion under the RISE Act, in line with the <u>PPC's recommendation for supplemental NIH funding</u>.

The Census stakeholder community is pushing for <u>\$400 million to cover costs related to the COVID-19</u> <u>pandemic</u>. The money would replenish the agency's contingency fund, which it may ultimately need for other unanticipated costs as it finishes the 2020 count.

The AAP is also actively advocating for robust policies to bolster the vaccine delivery system for children in light of concerning declines in childhood vaccination. The <u>advocacy agenda</u> focuses on increased financial support for childhood vaccination through Medicaid, the Vaccines for Children program, and other payment mechanisms. There is also a push to address vaccine hesitancy by passing the VACCINES Act, which will be essential to ensuring robust uptake when a COVID-19 vaccine is widely available.

RACIAL JUSTICE TAKES CENTER STAGE AS POLICE BRUTALITY, PANDEMIC HIGHLIGHT LONGSTANDING INEQUALITY IN COMMUNITIES OF COLOR. In a national environment dominated by the economic and

public health toll of the coronavirus pandemic, systemic racism has come to the fore of the public consciousness as long overdue action to combat racial inequality has taken on a new urgency. Driven by the brutal killings of George Floyd and countless others at the hands of police, policymakers and everyday Americans are contending with the role that systems and practices that have rarely been given a second thought play in perpetuating unequal outcomes for Black Americans and other people of color.

In the immediate aftermath of nationwide protests following Floyd's killing, bipartisan consensus emerged on Capitol Hill about the need for police reform legislation to address brutality by law enforcement and other systemic ills in the criminal justice system. Indeed, the <u>sheer support from</u> <u>politicians of all stripes</u> highlighted the dramatic change in public sentiment on issues of racial inequality. With the blessing of top Republican and Democratic leadership, lawmakers rushed to assemble packages that could be passed into law.

House Democrats and Senate Republicans quickly developed separate police reform legislation. The <u>House proposal</u>, <u>led by Rep. Karen Bass (D-Calif.</u>), would ban chokeholds and no-knock warrants, while making it easier to sue police officers in civil court. On the other side of the Capitol, <u>the Senate proposal</u>, <u>led by Sen. Tim Scott (R-S.C.</u>), seeks to incentivize reform in police departments across the nation by conditioning federal law enforcement funding on implementing policies like chokehold bans. The <u>House passed its police reform legislation</u> just before the July 4th recess. However, <u>Senate Democrats blocked Scott's proposal</u> from moving forward, and <u>Republicans and Democrats remain at odds</u> over the contours of any final legislation. If a police reform package is to pass out of Congress, <u>these key differences between the two chamber's proposals will have to be resolved</u>.

-Mounting Evidence of COVID-19 Impact on Communities of Color Compounds Urgency for Change. In the early days of the coronavirus pandemic, a disturbing picture began to emerge about the disproportionate impact of COVID-19 on Black Americans. However, piecemeal data collection on race in COVID-19 diagnoses stymied efforts to better understand which communities bore the brunt of the disease and implement targeted interventions, leading Congress to require the Centers for Disease Control and Prevention (CDC) to regularly report such data in the CARES Act.

Since that time, reports have consistently shown the <u>heightened impact of the virus on communities of</u> <u>color nationwide</u>. One article outlining the ways in which the health and economic effects of the virus have dovetailed with outcries over racial justice describes a "<u>pandemic within a pandemic</u>." The deleterious effects of the virus hold for other groups, including <u>Latinos</u>, and <u>new research shows</u> that people of color are <u>more likely to die of COVID-19 at a younger age</u> than white individuals. Reporting also indicates that <u>American Indian tribes have struggled to get needed demographic data from the</u> <u>federal government</u> to understand how the virus is spreading on tribal lands. <u>Structural racism</u> that manifests in lack of access to community resources, poorer health care, and <u>the physiological impact of</u> <u>chronic stress endured from experiencing racism are at the heart of these inequities.</u>

Still, <u>missing data continues to mask the full impact</u> of the pandemic on communities of color months into the crisis, <u>prompting an apology from CDC Director Robert Redfield</u> for the agency's inadequate data collection efforts.

CONGRESS BEGINS DELAYED GOVERNMENT FUNDING PROCESS AS END OF FISCAL YEAR APPROACHES.

With a full docket and the November election around the corner, Congress is slowly but surely returning to work on annual appropriations bills ahead of the September 30 government funding cliff. The often-fraught process that can deadlock Congress in the best of years has been scrambled by the COVID

pandemic, forcing congressional appropriators to reevaluate spending priorities on a dramatically truncated timeline. Further complicating matters, Congress is still operating under strict budget caps set by a bipartisan budget agreement reached well before the pandemic, which will limit any potential funding increases and may force Congress to make emergency appropriations outside of the caps for some programs.

The House Appropriations Committee released its proposed funding bill for HHS in early July, which was subsequently <u>approved in a party line vote on July 8 by the HHS subcommittee</u>. The bill provides a total of \$47 billion for NIH in Fiscal Year (FY) 2021, a \$5.5 billion increase over the NIH's currently enacted funding level. Of that \$5.5 billion increase, \$500 million would be designated for the agency's FY 2021 spending authority, while <u>\$5 billion would be made as emergency appropriations</u> to offset costs related to COVID research disruptions. That money will be available to the agency through FY 2025 and would be provided to the Office of the Director to distribute across the agency. The <u>research community voiced</u> tempered support for the proposal but urged that the supplemental spending provided in the bill ultimately be paired with additional emergency spending amounting to a total of \$10 billion.

The House spending bill would also double the amount of spending on firearm morbidity and mortality prevention research to \$25 million each at the NIH and the CDC, while increasing the Agency for Healthcare Research and Quality's budget by \$5 million. House appropriators expect to finish their work on FY 2021 spending bills by mid-July, with floor votes on most by the end of the month. The Senate will need to advance its own spending bills, but <u>the process has stalled out</u> amid contentious debates over police reform and additional COVID relief.

RESEARCH STUDIES ON COVID IN KIDS MOVE FORWARD BUT OTHER LIFESAVING RESEARCH IS

DELAYED. Months into the COVID-19 pandemic, major questions remain about the ways in which SARS-CoV-2 impacts children, and research has begun to find answers to outstanding questions, including the potential role children play in transmitting the virus. Recently published studies have <u>suggested that children are only half as likely as adults to get infected</u> with the coronavirus, though the <u>evidence remains weak</u>. Research has also shown that <u>infants have a higher SARS-CoV-2 viral load but less severe symptoms</u> than older children and adolescents, highlighting the need to study the virus in children across the pediatric age range. Research is ongoing to evaluate <u>drugs prescribed to children with COVID-19</u>, and the <u>All of Us Research Program has announced plans</u> to investigate COVID-19 in enrollees, though the program continues to enroll only those over age 18. In a sign of the importance of understanding the virus in children, presumptive Democratic presidential nominee Joe Biden included a prominent <u>mention of increased funding for pediatric research on coronavirus</u> in his plan for reopening the economy.

Despite signs of progress from COVID research, the pandemic has upended medical research for deadly rare diseases. This Washington Post article details the <u>impact the shutdown has had on research into</u> <u>Lafora disease</u>, chronicling one family's experience participating in biomedical research and grappling with the reality of slowed progress due to the pandemic. The experience underscores the need for dramatic supplemental infusions of funding for the NIH and other agencies to ensure research areas on the cusp of breakthroughs are not lost or dramatically slowed.

CENSUS BUREAU MEETS INITIAL RESPONSE GOALS. In early June, the <u>Census Bureau announced that</u> 60.5% of households had responded to the 2020 Census, meeting initial completion targets despite the coronavirus. Data indicate that the majority of households responded online. The agency has <u>slowly</u> <u>started field operations</u>, the next stage in completing the count to reach those who have not yet filled

out their forms. The Census advocacy community has <u>requested \$1.681 billion</u> for the agency in the coming year through the appropriations process, which will be important to helping finish the Census.

SUPREME COURT RULINGS REPRESENT WINS FOR DREAMERS, LGBTQ AMERICANS. On June 18, the U.S. <u>Supreme Court ruled that the Trump administration's attempt to end the Deferred Action for</u> <u>Childhood Arrivals (DACA) program was unlawful</u>. The DACA program allows more than 700,000 young people who were brought to the United States as children to live and work here. However, the ruling does not preclude the administration from trying to end the program again.

Days earlier, the Court held that <u>sex-based protections from employment discrimination under Title VII</u> of the Civil Rights Act apply to LGBTQ individuals. The landmark ruling bars employment discrimination on the basis of sexual orientation and gender identity for the first time. While the ruling does not directly impact a recent <u>Trump administration rule rolling back nondiscrimination protections for LGBTQ</u> individuals in health care, many legal experts and advocates anticipate that <u>the Court's ruling will be</u> used to invalidate the rule.

PPC POLICY COMMENTARIES. Members of the PPC have authored commentaries detailing the policy implications of research published in *Pediatric Research*. You can read these PPC-authored commentaries online:

 <u>COVID-19 impact on research, lessons learned from COVID-19 research, implications for</u> <u>pediatric research</u> by Debra Weiner, MD, Vivek Balasubramaniam, MD, Shetal Shah, MD, and Joyce Javier, MD, MPH,MS

<u>The vapes of wrath: advocating to protect children from electronic nicotine systems in the age of flavored vapes</u> by Shetal Shah, MD, Joyce Javier, MD, MPH, MS, Heather Brumberg, MD