

ACADEMIC AMERICAN PEDIATRIC PEDIATRIC ASSOCIATION SOCIETY ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRS SOCIETY FOR PEDIATRIC RESEARCH

PPC CAPITOL CONNECTION

June 11, 2019

What Matters Now in Washington:

- The House Appropriations Committee has proposed \$50 million in funding for gun violence prevention research in FY20, as well as \$2 billion more for the National Institutes of Health. <u>More...</u>
- The federal government proposed eliminating civil rights protections for transgender individuals in health care. <u>More...</u>
- Researchers seeking to use fetal tissue in biomedical research will soon face additional scrutiny following a recent decision by HHS. <u>More...</u>
- Hundreds of thousands of children lost coverage through Medicaid and the Children's Health Insurance Program in 2018. <u>More...</u>
- HHS is enhancing conscience protections for health care workers in a move that may undermine access to some health care services. <u>More...</u>
- The Trump administration released a rule restricting provider speech through the Title X Family Planning Program, but federal courts have put the rule on hold for the time being. <u>More...</u>

FOR FIRST TIME IN DECADES, HOUSE APPROPRIATORS ADVANCE \$50 MILLION FOR GUN VIOLENCE PREVENTION RESEARCH IN FY20. In a major win for pediatric research, the House Appropriations Committee included \$50 million for gun violence prevention research in its Fiscal Year (FY) 2020 funding bill for the Department of Health and Human Services (HHS). This funding, split evenly between the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), would provide a necessary injection of resources into a field of research that has largely laid dormant since federal funding for research into the prevention of firearm-related injury and death was shelved in the 1990s. The PPC has been instrumental in the coalition that worked to secure this initial victory, developing the appropriations ask of \$50 million that was adopted by 166 medical and public health organizations and advanced by House champions of gun violence prevention research.

—House of Representatives Set to Increase Overall HHS Funding, Including Multi-Billion Dollar Increase for NIH. In addition to the notable inclusion of funding for gun violence prevention research, the <u>House Appropriations Committee approved major funding increases</u> across the Department of Health and Human Services. Building on a multi-year commitment to the NIH, House appropriators have proposed \$41.1 billion in FY 2020, a \$2 billion increase over current funding and more than \$6 billion above the Trump administration's budget request for the biomedical research funder. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) would receive a \$73 million funding increase. House appropriators also chose to invest in other pediatric research and training priorities, including a \$20 million funding increase for the Agency for Healthcare Research and Quality, or \$358 million in aggregate, and a \$25 million increase for the Children's Hospital Graduate Medical Education (CHGME) program, for a total of \$350 million. In a full committee markup in early May, the House Appropriations Committee considered and ultimately rejected an amendment prohibiting the use of federal funding for fetal tissue research and went on to pass the HHS funding bill along party lines. The HHS FY20 funding bill will come to the full House of Representatives for a vote in the coming months, where it is likely to be approved.

-As House Develops Opening Bid on FY20 Spending, Budget Caps Loom. Despite a strong initial funding proposal from House appropriators, significant work remains before a final appropriations package can be enacted with generous increases for pediatric research priorities. Most critically, Congress must act to lift the budget caps set by the Budget Control Act of 2011 (BCA) or risk triggering draconian across-the-board cuts to discretionary spending. This will require a bipartisan deal that can win the approval of President Trump raising both defense and non-defense discretionary spending levels in the coming fiscal year. Congress has acted multiple times to lift the caps in recent years, enabling NIH's multi-billion-dollar increases. However, it is far from clear that a deal can be struck this year, as partisan tensions run high and Republicans in the Senate look to assert their vision for federal spending that may conflict with the House proposal. Beyond the budget caps, Senate appropriators are working right now to develop their own FY20 funding proposal, and many are expecting the Senate's bill to be far more conservative in an effort to align their spending with the cuts that will be required if a bipartisan budget deal is not reached.

HHS PROPOSES ROLLBACK OF PROTECTIONS FOR LGBT PATIENTS. In a long-anticipated rulemaking, the Department of Health and Human Services (HHS) proposed eliminating nondiscrimination protections for transgender people in health care. Released in late May, the proposed rule makes major revisions to the federal government's current regulations implementing Section 1557 of the Affordable Care Act (ACA)—the ACA's main nondiscrimination provision. As passed by Congress, Section 1557 extends federal civil rights protections to federally funded health care programs. A rule finalized by the Obama administration in 2016 interpreted sex discrimination to mean discrimination on the basis of gender identity. However, the Trump administration rule would limit civil rights protections to those being discriminated against on the basis of biological sex. The proposed rule also removes protections for sexual minority individuals and for women who have chosen to terminate a pregnancy. Transgender individuals frequently report being denied care on the basis of their gender identity.

NEW RESTRICTIONS ON FEDERALLY FUNDED FETAL TISSUE RESEARCH ROLLED OUT FOLLOWING

MONTHS-LONG REVIEW. After a 9-month review of the practice, <u>federal officials have announced</u> they will place heightened restrictions on the use of human fetal tissue in biomedical research. The decision was made public on May 5, when HHS <u>let a research contract with the University of California San</u> <u>Francisco (UCSF) expire</u> after temporarily extending it several times. UCSF researchers were using human fetal tissue to study HIV through humanized mice models. The <u>new policy</u> will bar the use of fetal tissue in NIH intramural research, a move that is expected to impact 3 studies in the intramural research portfolio. The policy leaves currently funded extramural research untouched. However, it subjects future studies that have made their way through the competitive grant process to a newly created ethics advisory board. A board recommendation against the use of fetal tissue in an otherwise approved study would empower the HHS Secretary to intervene to halt the study. Such a board is authorized under a decades-old law but has been rarely, if ever, used. The federal government also announced \$20 million to develop and validate alternative models to fetal tissue research. The decision to implement these restrictions was <u>ultimately made by the President</u>, who overruled HHS Secretary Alex Azar in a move that has been widely celebrated by anti-abortion groups.

AFTER YEARS OF GAINS, CHILD ENROLLMENT IN HEALTH COVERAGE SHOWS SIGNS OF RECEDING. New data show that the number of children enrolled in Medicaid and the Children's Health Insurance Program (CHIP) fell by about 840,000 in 2018. These coverage losses, which were seen in states around the country, come as the federal government has advanced numerous policies that make it more difficult for children and families to enroll in quality, affordable health coverage through Medicaid, CHIP, and the individual market. While researchers have yet to validate the cause behind these coverage declines, these coverage losses are concerning, particularly after the U.S. recently reached historic lows in uninsurance for children.

HHS ROLES OUT NEW CONSCIENCE PROTECTIONS RULE THAT MAY THREATEN ACCESS TO CARE FOR MARGINALIZED POPULATIONS, SENSITIVE SERVICES. Earlier this month, the Trump administration finalized a new rule to <u>strengthen health care workers' ability to refuse to provide care</u> on the basis of religious or conscience claims. As finalized, the rule has the potential to <u>undermine access</u> to comprehensive reproductive health care and care for individuals identifying as LGBTQ. Additionally, there is concern that the rule could reduce access to vaccination, as health care providers opt out of administering certain vaccinations derived from fetal tissue. The rule comes as part of a broader set of actions by the federal government to elevate religious freedom, including the creation of a Division of Conscience and Religious Freedom within the HHS Office for Civil Rights, which has historically enforced antidiscrimination civil rights laws.

FEDERAL COURTS HALT TRUMP ADMINISTRATION REWRITE OF FAMILY PLANNING PROGRAM. The Trump administration's Title X Family Planning Program Final Rule has been <u>placed on hold by multiple</u> <u>federal judges</u>. More than 20 states, health care provider groups including the American Medical Association, and Title X clinics filed suit in federal courts around the country challenging the recently published rule, which threatens to severely restrict access to comprehensive family planning services for adolescents and young adults and compromise the quality of care they are able to receive through the program. These rules made <u>multiple concerning changes</u> to Title X, the only federal program dedicated to providing adolescents and low-income adults with access to comprehensive family planning services, including regulating the way providers can counsel about family planning (the so-called "gag rule"), compromising adolescent confidentiality, and making many current Title X recipients ineligible for funding through the program. Health care providers have been outspoken in opposition to this rule, engaging in the regulatory process and litigation to ensure continued access to evidence-based reproductive health care for young people. The Title X program will continue in its current form until a final determination has been made by the courts.

NICHD AND ECHO DIRECTORS CALL ATTENTION TO IMPACT OF OPIOIDS ON CHILDREN. In an editorial in the American Journal of Obstetrics and Gynecology, Diana Bianchi, MD, NICHD Director, and Matthew Gillman, MD, Environmental influences on Child Health Outcomes (ECHO) Director, emphasized the substantial burden facing women and children of childbearing age in the U.S. opioid epidemic. <u>Read</u> <u>more.</u>